Royal College of Physicians

Asthma Audit Development Project (AADP)

Phase 2: Final report (August 2018)

The Royal College of Physicians

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Healthcare Quality Improvement Partnership (HQIP)

The Asthma Audit Development Project (AADP) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the NCAPOP, comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual audits, also funded by the Health Department of the Scottish Government, DHSSPS Northern Ireland and the Channel Islands.

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Section 1: Introduction and methodology

1.1 Introduction

1.1.1 Asthma

Asthma is a common, heterogeneous disease, usually characterised by chronic airways inflammation. It is defined by the history of respiratory symptoms including breathlessness, wheeze, chest tightness and cough that vary over time and in intensity, together with a variable expiratory airflow limitation.[1] Asthma results from many different mechanisms, each with different comorbidities and specific triggers. Asthma severity can vary from mild, requiring little treatment, to severe, requiring multiple treatments and repeated hospital admission. In severe cases, quality of life can be adversely affected, leading to difficulties with everyday activities, sleep and school and work attendance.

Asthma is the most common lung disease in the UK, with approximately 8 million diagnosed cases (12% of the population), up to 5.4 million people actively receiving treatment,[2, 3] and around 160,000 new diagnoses each year. Asthma accounts for 60,000 hospital admissions, 200,000 bed days,[3] approximately 6.4 million GP and nurse consultations and an estimated cost of £1.1 billion a year to the UK health service.[4]

Approximately 1,200 people die from asthma every year.[3] The National Review of Asthma Deaths (NRAD),[5] which collected and reviewed deaths from asthma for a year between 2012 and 2013, reported that care leading up to death was inadequate in 26% (n=51) of cases where asthma was confirmed as the cause of death (n=195) and identified potentially avoidable factors in:

- the management or adherence to guidelines (46% of the 195)
- the patient, their families and their environment (65% of the 195)
- routine care, supervision and monitoring from primary and secondary care (70% and 29% of the 195 respectively).

There is also a well-known link between asthma and mental health, with the prevalence of anxiety and depression being higher in people with asthma and these groups often experiencing poorer outcomes.[6,7]

1.1.2 The Asthma Audit Development Project (AADP)

Following a key recommendation from the NRAD report *Why Asthma Still Kills* that 'a national ongoing audit of asthma should be established, which would help clinicians, commissioners and patient organisations to improve asthma care',[5] asthma was proposed as a new topic to join the National Clinical Audit and Patient Outcomes Programme (NACPOP) in the NHS England call for audit topics in 2014.

The topic was evaluated and prioritised at the inaugural NHS England Domain Directors' Prioritisation Meeting for NCAPOP in March 2015, with feedback that it should cover adults and children, be established in secondary care, with the possibility of including ambulance data, and should be extended to primary care as soon as data extraction mechanisms were established.

In order to define and agree a clear focus which would be included in the specification of the new audit contract, the Healthcare Quality Improvement Partnership (HQIP) convened a task and finish group which consulted widely and met twice in the autumn of 2015. The group's final decisions were to commission:

- a feasibility project (the Asthma Audit Development Project [AADP]), to inform the specification of a National Asthma Audit, answer the question 'what initial approach should be adopted for an asthma audit', and carry out some of the foundation work needed prior to its launch
- a joint asthma and Chronic Obstructive Pulmonary Disease (COPD) audit programme to commence in March 2018 (ie following completion of both the National COPD Audit Programme and the AADP), subject to the usual commissioning and procurement processes.

The AADP was commissioned as a two-phased project and the Royal College of Physicians (RCP), London appointed as its provider.

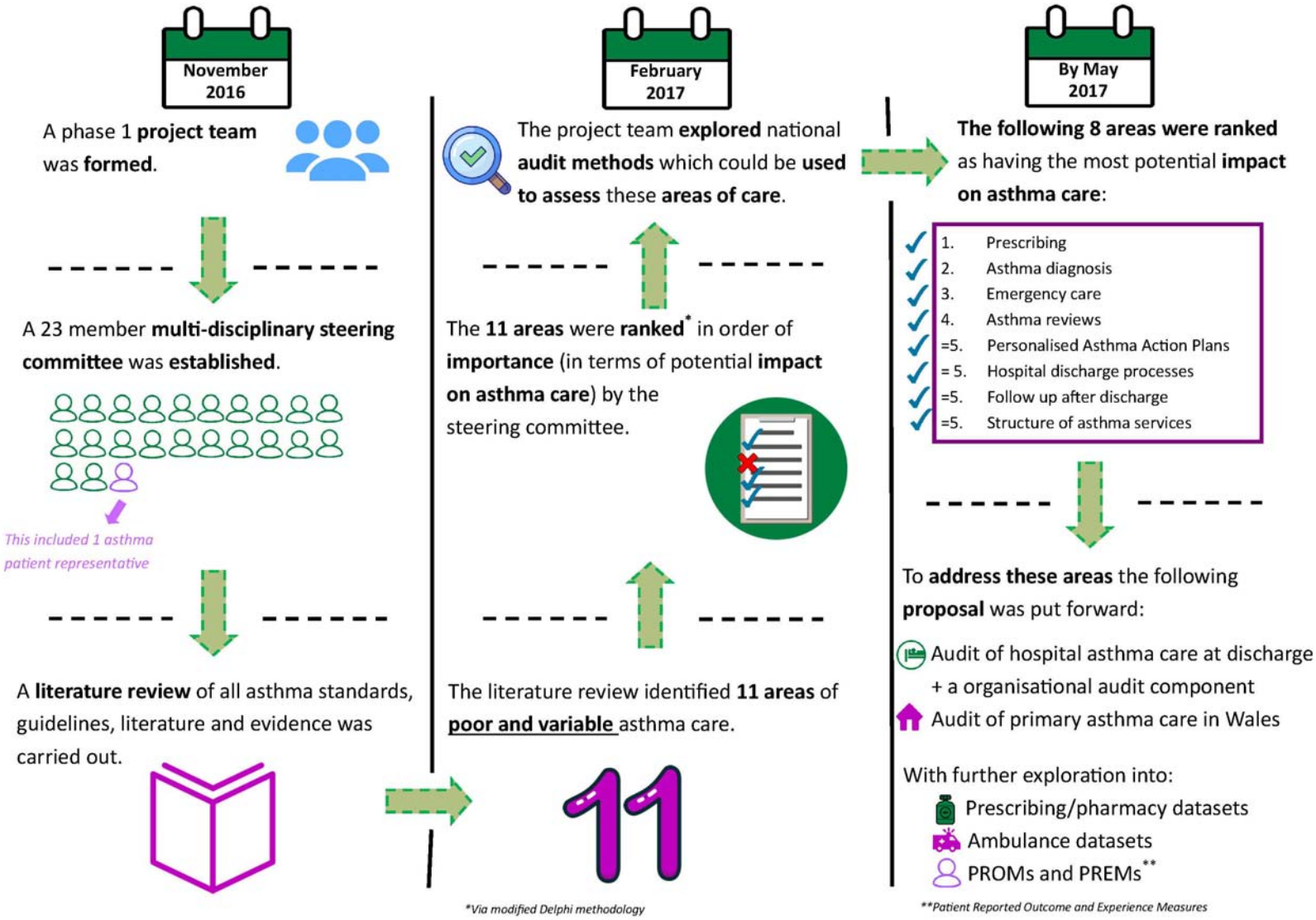
Phase 1

Phase 1 of the AADP commenced in November 2016, with the following objectives:

- to review the areas of poor and variable care for patients with asthma
- to consider the variety of possible national clinical audit designs
- to use the results of these activities to develop an options appraisal outlining two to four possible approaches for a National Asthma Audit.

Figure 1.1 provides a summary of the phase 1 methods and final proposal. Full details of the activities, findings and recommendations from phase 1 of the project can be found within the final report which is available at www.rcplondon.ac.uk/naadp.[8]

Figure 1.1 Summary of AADP phase 1 methods and final proposal



Phase 2

Following the acceptance of phase 1's proposal (see Figure 1.1) by funders and stakeholder groups, phase 2 of the AADP was launched with the following specific objectives:

- to design and deliver the phase 2 activity described in the selected option of the phase 1 appraisal
- to produce a report for HQIP on the work undertaken.

In order to meet these objectives, phase 2 of the AADP included:

- planning, designing, developing and testing the proposed audit methodology, secondary care datasets (adult and paediatric) and primary care queries
- exploring additional information sources, including pharmacy/prescribing, ambulance and patient reported outcome and experience measures (PROMS and PREMS).

This report outlines the steps taken to meet the objectives set and conclusions and proposed recommendations for next steps based on the activities of, and information obtained by, phase 2 of the AADP.

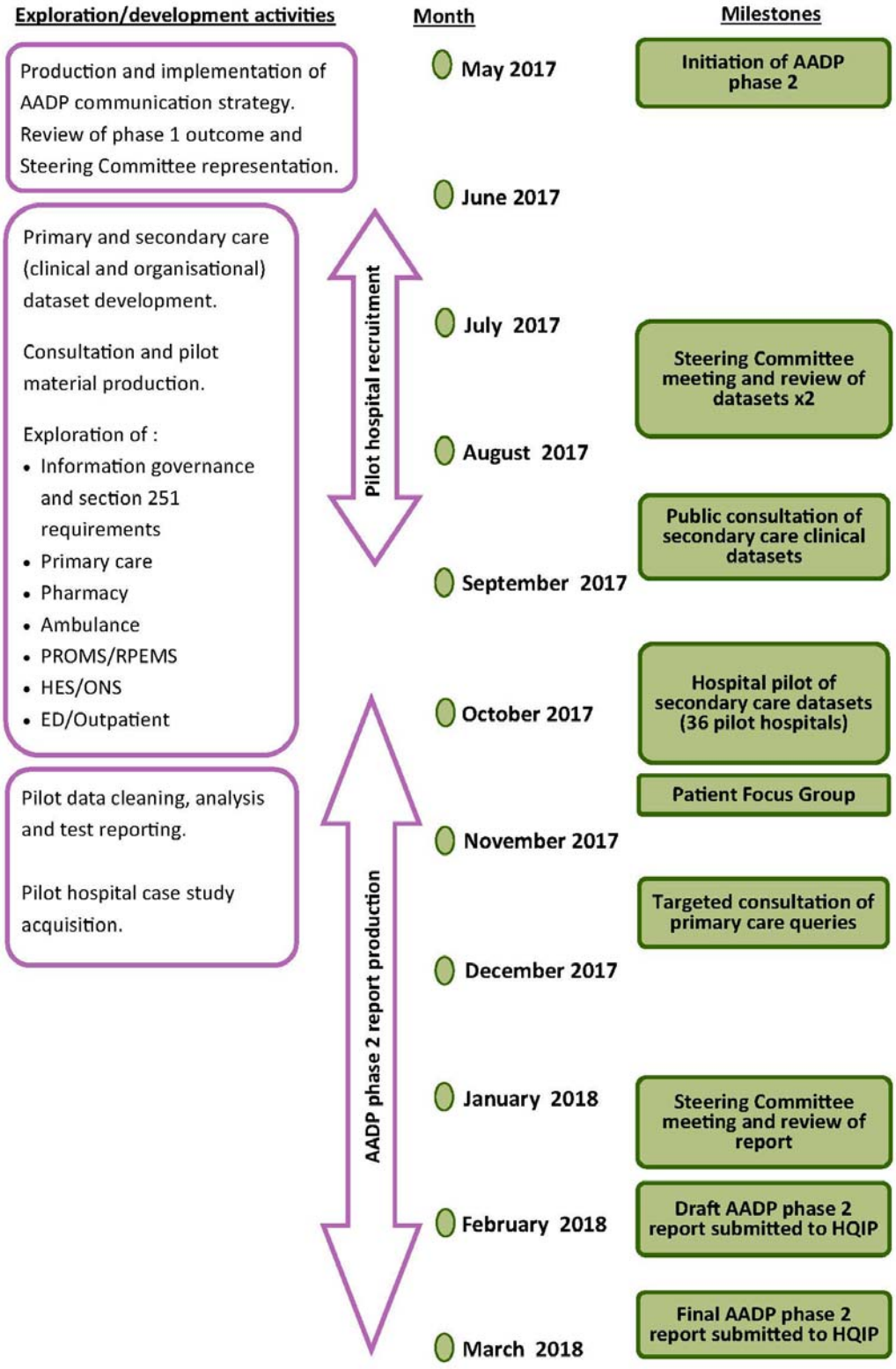
Following a Patient Focus Group held in October 2017, patient quotes have been used to highlight areas of asthma care that are of the most interest and importance to asthma patients and carers. These, and areas of the final datasets that were highlighted as of particular importance to patients during this focus group, will be shown accompanied by the patient symbol above. These help to provide a clear patient voice throughout the report, as well as some insight into the care currently being received from a patient's perspective.

Further details of the Focus Group and how it was used to inform the structure and consent of the proposed National Asthma Audit can be found in section 2 of this report.

1.2 Phase 2 – Summary of timelines and methodology

Phase 2 of the Asthma Audit Development Project (AADP) commenced in May 2017, following acceptance of the phase 1 report and proposal. Figure 1.2 provides a summary of the timelines and methodology followed for phase 2.

Figure 1.2: Summary of AADP phase 2 timelines and methodology



Section 2: Patient involvement

Patient involvement in the Asthma Audit Development Project (AADP) was central to its success, as it ensured asthma patients and their carers had the opportunity to be involved in the planning and development of the proposed National Asthma Audit.

Outlined below are details on how asthma patients and carers were involved in the AADP and how their views and feedback were sought on both project activity and the areas of asthma care that were most important to them.

2.1 Patient involvement in the AADP

Relevant patient charities – Asthma UK and the British Lung Foundation (BLF) – and an asthma patient representative were identified and invited to be part of the AADP steering committee during phase 1. This representation continued and patient views were sought at every available opportunity. Both Asthma UK and the BLF were provided with regular updates on project progress and information and asked to disseminate this as appropriate.

2.2 Asthma patient views and feedback

In October 2017 a Patient Focus Group was held by Asthma UK. The focus group was set up to seek asthma patient and carer views and feedback on what aspects of asthma care were most important to them and on the proposed National Asthma Audit methodology and content. The objectives of the focus group were:

1. to ensure that asthma patients had the opportunity to:
    a. discuss what matters most to them about the care they receive when:
        i. they are admitted to hospital
        ii. they visit their local GP surgery
        iii. younger people transfer from paediatric to adult services
    b. review and comment on the layout and possible content of a draft patient-friendly asthma report
    c. discuss potential PROMS/PREMS – what are the most important questions to ask about the care they receive in primary and secondary care.
2. to ensure that there is a strong patient voice within the phase 2 report and in the development of the proposed national asthma audit.

2.2.1 Methodology

Asthma UK was provided with the above objectives and information about the types of attendees required at the group (as broad a diversity as possible with respect to asthma severity, age, gender, ethnicity and geographical location). Following this, nine asthma patients and carers were recruited to attend the Patient Focus Group on Saturday 21 October 2017, all of whom consented to their quotes being used in the final phase 2 report.

The AADP team produced two example patient-friendly report sections to enable discussion around the preferred format of information. In addition to this, using the information and objectives provided, Asthma UK produced a topic guide to ensure all topics were covered during the meeting.

The Patient Focus Group was held in an open forum format, with the meeting facilitator using the topic guide to direct the discussion, ask questions and address subjects which had not come up organically.

2.2.2 Results

Several common themes emerged during the focus group. These were:

- the importance of looking at different groups (demographics), particularly in children
- routine asthma care, particularly an awareness of triggers, annual asthma reviews and inhaler technique checks
- GP level statistics for patients
- during emergency care, the importance of assessing exacerbation severity correctly and ensuring the appropriate treatment is given
- that outputs from the National Asthma Audit should help to inform patient choice and increase their awareness of the care they should be receiving and their ability to campaign for better care
- that outputs should be clear, concise and consistent in format and appearance.

The findings from this Focus Group were used when making decisions on the final secondary and primary care datasets (see sections 3 and 4) and, where possible, areas/data items which were of importance to asthma patients and carers, and could be addressed by the National Asthma Audit, were incorporated. Some themes and areas of asthma care raised were considered outside the proposed audit scope (eg GP-level statistics for patients or potential research proposals) and therefore cannot be captured by this programme of work.

A full copy of the summary report from the Focus Group is available in appendix 26.

2.2.3 Patient views on a National Asthma Audit

As part of the Focus Group held in October 2017, asthma patients and carers were asked how a National Asthma Audit is important to them. The quotes below provide details on some of the responses received to this.

What is important to asthma patients and carers about a National Asthma Audit?

The information it would provide [obtainable from primary and secondary care audits]
'You'd want to know how many patients have got asthma, have they seen those patients, have they done reviews, have they got plans in place for all of those patients.'

'Gold standard' care [obtainable from primary and secondary care audits]
'So, surely the national audit's actually going to be identifying some of that, or it should be. So, does it make an impact if people do actually attend their reviews or don't? I mean, we assume it's a good thing. But actually is the evidence there that it is…'

Information for patients on what care should be being provided [obtainable from primary and secondary care audits]
'… you are in a position to maybe ask them some questions about, am I not also, not gonna have,… Let's take it that you know the seven things, and they're only giving you four. You can say, where are the other three things please to help me manage my condition?'

Section 3: Development of secondary care audits

3.1 Overview

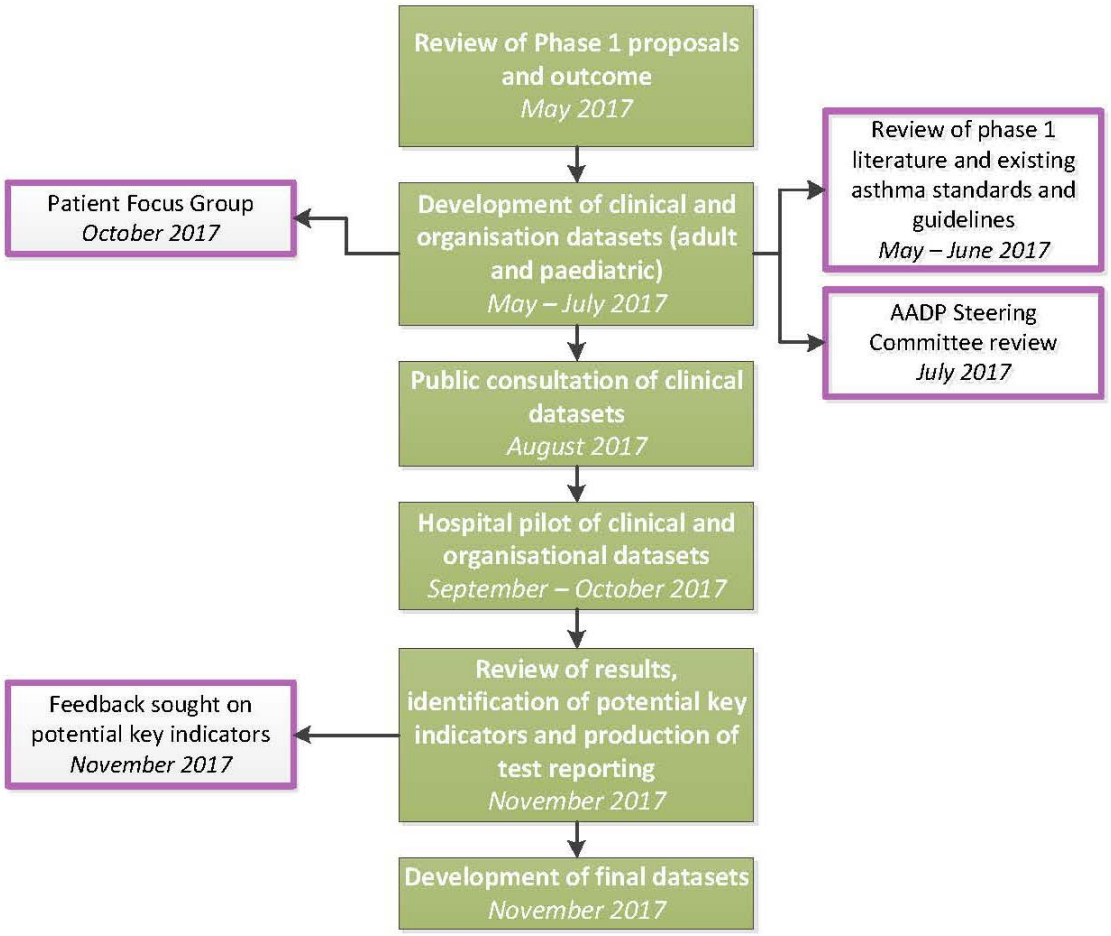
Final proposal from Phase 1 of the AADP

The statement below outlines the final proposal for the secondary care component of the National Asthma Audit.

'Secondary care audit of adult and paediatric asthma care, at discharge but covering other areas of the secondary care asthma pathway where possible, with a snapshot organisational audit component.'

Following the outcome for phase 1 and to meet the objectives for phase 2 outlined in section 1, planning, development and testing work was carried out for the secondary care component of the National Asthma Audit. Figure 3.1 provides an overview of the work included.

Figure 3.1 Overview of secondary care audit development



This section will outline the timescales and development activities undertaken to produce the secondary care audit methodology and datasets.

3.2 Development of the secondary care datasets

With approximately 60,000 people admitted to hospital each year with an acute exacerbation of asthma, [3] the secondary care environment requires healthcare professionals to:

- assess the severity of the exacerbation and gain familiarity with that person's asthma quickly in order to ensure correct treatments are administered without delay. There are guidelines (BTS/SIGN 153 and NICE Quality Standard [QS25]) that cover the care patients should receive when in hospital for asthma exacerbations. Examples include administration of systemic steroids within one hour for severe and life threatening exacerbations of asthma, and within four hours for moderate exacerbations of asthma
- ensure discharge processes from hospital, as such following a formal discharge bundle, are adhered to for every patient so that the risk of future exacerbations and hospital admissions is reduced.

The aim of the secondary care audit development process was, therefore, to ensure that methodologies and datasets were mapped closely to guidelines and standards and to keep clinical burden to an absolute minimum.

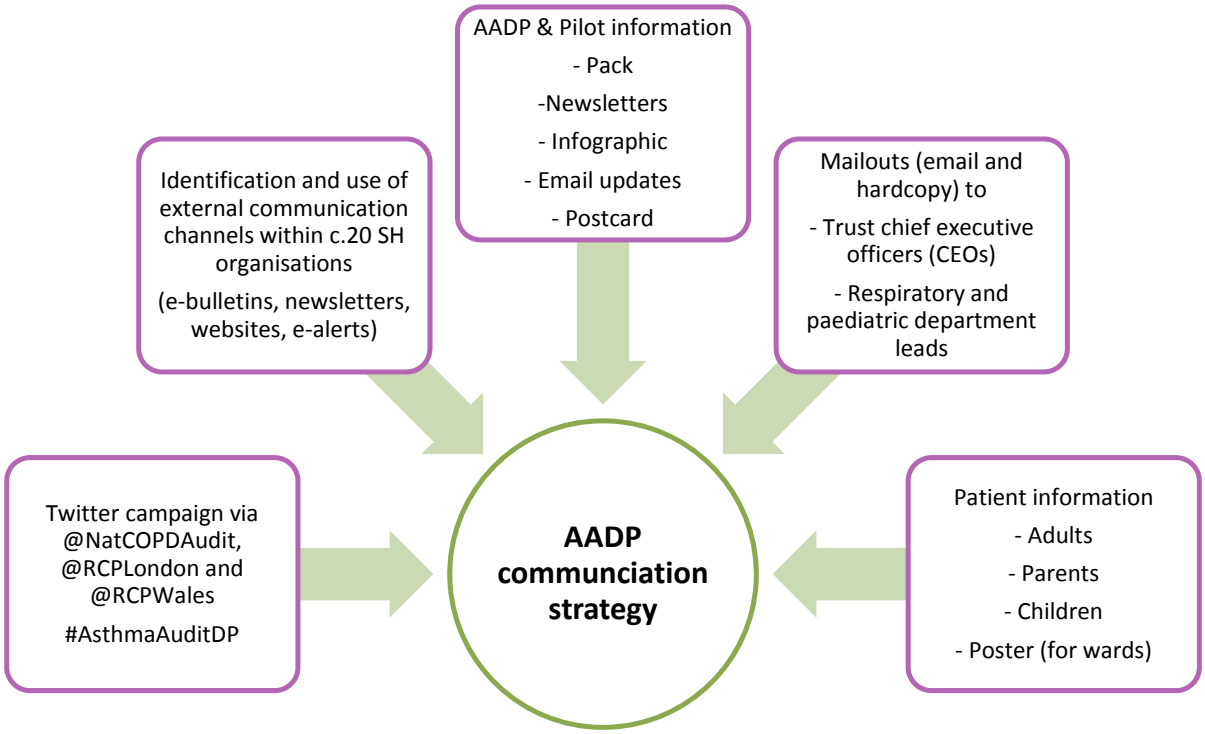
3.2.1 Communication strategy

In May 2017, a comprehensive communication strategy was developed and implemented, with the following aims:

- to raise awareness of the AADP and forthcoming National Asthma Audit
- to engage all necessary stakeholders, including asthma patients
- to ensure messages and information about the AADP were spread as broadly as possible
- to address barriers and concerns about clinical burden of the asthma audit
- to promote public consultation of the clinical datasets
- to recruit pilot hospitals and provide them with the information needed to participate
- to seek feedback on potential key indicators.

Figure 3.2 provides an overview of communication methods used in order to ensure these aims were achieved.

Figure 3.2 AADP communication strategy overview



The success of this communications strategy can be demonstrated by:

- the public consultation and responses received
- the number of pilot hospitals that registered and participated in the hospital pilot
- the dissemination of pilot materials prior to and during the pilot process
- the production and availability of patient/carer/parent information
- the key indicator survey and responses received.

Further information on the pilot, public consultation and key indicator survey specifically can be found within sections 3.2.3 and 3.2.4 of this report.

Many of the materials outlined above are accessible via the AADP webpages.[8]

3.2.2 Development methodology

All existing asthma evidence, guidelines, standards and audits were explored in May 2017 to identify individual elements of recommended asthma care (eg systemic steroids within 1 hour). This was done specially to inform the content of the secondary care datasets and address all areas of asthma care which had been identified as poor or variable in phase 1.[9] It included:

- *BTS/SIGN 153: British Guideline on the management of asthma. A national clinical guideline.* (2016)[10]
- *NICE Quality Standard [QS25]: Asthma.* February 2013[11]
- The National Review of Asthma Deaths (NRAD): *Why asthma still kills*. (2014)[5]
- British Thoracic Society (BTS): Adult & Paediatric audit datasets and discharge bundle[12,13,14]
- Royal College Emergency Medicine's asthma audit dataset and recommendations[15]
- National COPD Audit Programme datasets[16]

(The new NICE guideline (NG80) – Asthma: diagnosis, monitoring and chronic asthma management (November 2017) – did not address hospital treatment of asthma, therefore no changes to the secondary care datasets were required as a result.)

The information gathered from this work was used to produce initial datasets for all secondary care components by June 2017, namely:

- adult clinical and organisational audits
- paediatric clinical (1–5 years and 6–18 years) and organisational audits.

Secondary care clinical audit datasets

The clinical datasets were designed for continuous audit and, therefore, the number of data items needed to be kept to a minimum (approximately 25 per dataset) to enable completion within 10–15 minutes per patient (deemed to be feasible in the reduction of the National COPD Audit dataset for continuous audit, post AADP public consultation and piloting. It is also in keeping with other datasets with equivalent patient throughput). For each proposed data item, evidence and rationale obtained from the above sources was provided and a MOSCOW rating (Must have, Should have, Could have, Will not) assigned to each to aid discussion and decision making.

The clinical datasets were developed for an audit conducted at the point of discharge. However, data items covering psychosocial factors, pre-hospital care and acute care were incorporated to give insight into care and treatment across the entire asthma secondary emergency care pathway.

Secondary care organisational audit datasets

With the proposal for the national COPD and asthma audits being jointly administered, it was considered appropriate to develop the asthma adult and paediatric organisational datasets based on the content of the existing National COPD Audit Programme organisational audit. This would ensure that services were being measured and compared accurately and consistently (where appropriate) and provide the opportunity for the adult asthma and COPD organisational audits to be run together, reducing clinical burden and audit resource without compromising the quality of the audit findings.

Data items within the existing National COPD Audit Programme organisational dataset were therefore adapted where necessary to incorporate asthma and/or paediatrics. Clinical expertise was sought to ensure that the paediatric data items especially were appropriate to paediatric services and could accurately reflect the asthma service provided. Following strong views around capturing the provision of transitional care, a new section on this was also added.

Details of all clinical and organisational data items considered but not included or removed during the refinement process can be found in appendices 13–16.

3.2.3 Public consultation

In August 2017, a public consultation of the secondary care clinical datasets was held. This process ensured that all stakeholders, including asthma patients and their carers, could take part in dataset development, and provided additional opportunity for refinement ahead of the planned hospital pilot. Both adult and paediatric datasets, helpnotes and the rationale were made available via the RCP webpages and extensive communication and awareness-raising activities took place in order to ensure the invitation to participate was disseminated as widely as possible.

Twelve responses (details of respondents can be found in appendix 5) were received between 31 July and 20 August 2017, containing approximately 60 comments, which provided:

- useful indications of where data items, helpnotes and the rationale needed refining
- additional evidence for the removal of data items
- information on which data items could be extracted from electronic records/hospital systems, rather than requiring individual review of clinical records.

Although some concerns were raised about the length of dataset, no anxieties about the audit in general were submitted. Positive comments about the audit and its potential impact were, however, received, an example of which is provided below.

> **Dr Will McConnell**
> Consultant respiratory physician, Dorset County Hospital
> *'This dataset seems very good and achievable.'*

Using this feedback all datasets and associated material were streamlined further, to approximately 20 data items (excluding patient identifiers).

3.2.4 Hospital pilot of clinical and organisational datasets

36 geographically dispersed hospitals were recruited to participate in the AADP hospital pilot between June and August 2017. These included a range of adult and paediatric hospitals, as well as of district general hospitals and university teaching hospitals.

Requirements

Pilot hospitals were asked to do the following as part of the AADP pilot process:

- formally register, identifying at least one clinical lead and one audit department contact
- inform their Caldicott guardian and submit the signed Caldicott guardian form, if necessary
- collect 15 adult and/or 15 paediatric clinical datasets for patients admitted to hospital with an acute exacerbation of asthma within the pilot period
- collect the organisational data (as appropriate)
- submit all clinical and organisational data via paper forms or Excel data template, along with feedback on the datasets
- (optionally) submit a case study on how their hospital integrated the new asthma audit process into their existing clinical processes.

Due to adult services having just completed the organisational audit for the National COPD Audit Programme, they were asked to pilot new and substantially amended data items only.

Timescales

Timescales for the pilot process are outlined in Figure 3.3.

Figure 3.3 AADP pilot process timescales

Methodology

Pilot materials were produced and sent to all pilot hospitals two working days (four calendar days) ahead of the pilot start date. These included:

- clinical and organisational datasets, helpnotes and rationale
- paper forms, formatted to allow direct data entry and feedback
- Excel-based data templates (one adult, one paediatric), containing simple data validations to aid data entry and testing of the proposed audit data items (piloting of the data entry methodology – ie via a webtool – was not included in the scope of the AADP)
- quick reference guide to the clinical datasets
- patient information sheets and posters.

Materials were sent via Mimecast which enables tracking of access to materials and, therefore, the initiation of general and tailored chasing activities. Chasing continued until the final deadline date and the submission of all expected data.

A helpdesk was established and enabled audit leads to make direct contact with the AADP team when required. Newsletters were produced and sent regularly to ensure continued engagement and access to up to date information, including FAQs identified via the helpdesk. Pilot hospitals were required to submit data by paper forms or the Excel based data template. Data submitted in any other way was not accepted.

A case study template form was produced and made available to those pilot hospitals who had expressed an interest in submitting a case study.

Inclusion criteria

Patients admitted to hospital with a primary diagnosis of asthma (J45-46). Children between 1–5 years old, admitted with wheeze that was responsive to salbutamol (R06.2), were additionally included. Admission was required to be between 11 September and 6 October 2017 to ensure that the methodology for a prospective, continuous audit at discharge was tested, and that data could be collected and submitted by the final deadline. If a hospital did not admit 15 patients meeting the inclusion criteria within the pilot period, they were asked to submit all eligible cases.

Data cleaning and analysis methodology

All submitted data was collated into master data templates and submitted to Imperial College London for data cleaning and analysis.

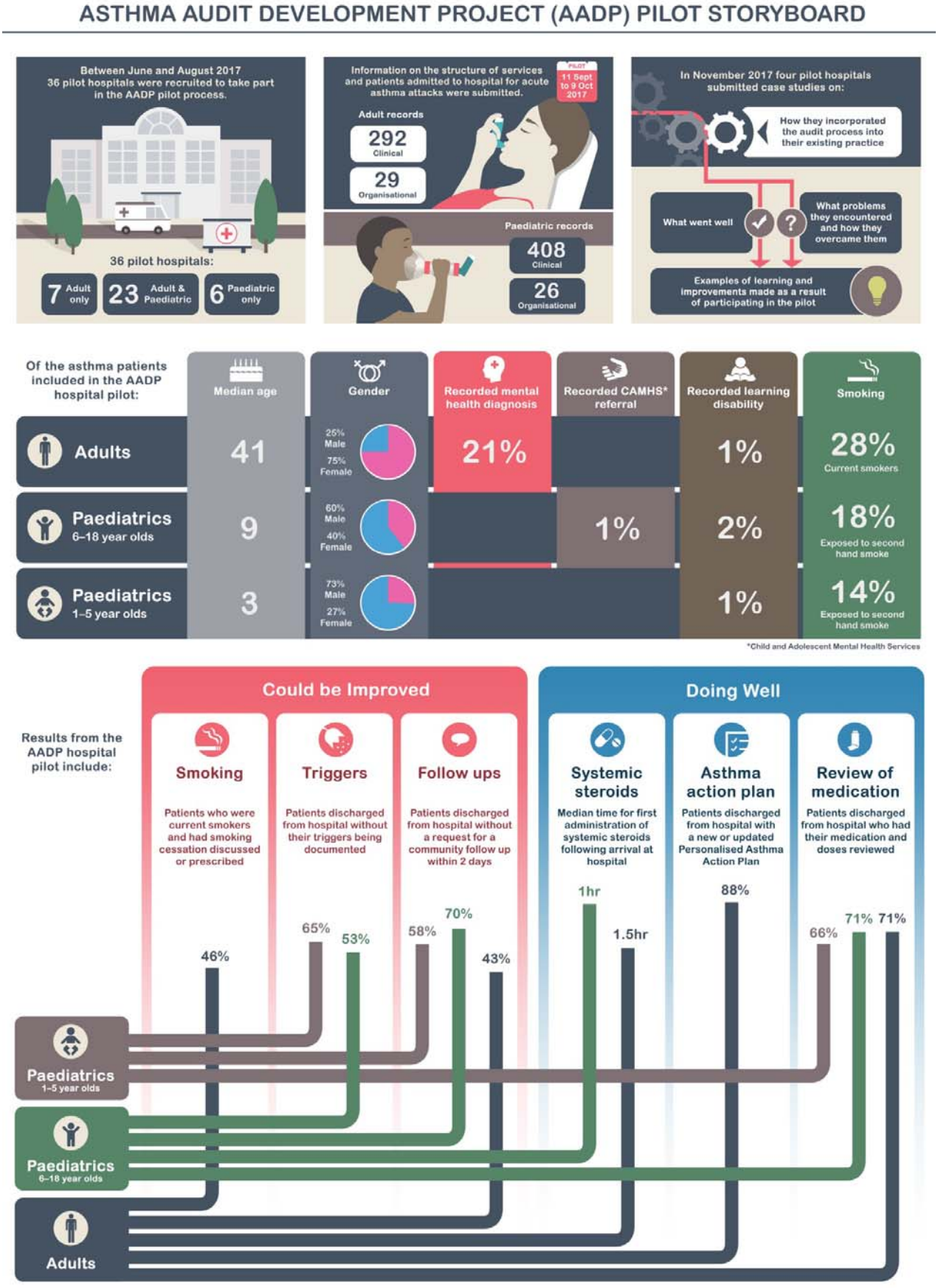
Data cleaning exercises were carried out and any necessary queries regarding seemingly illogical or incorrect data were sent to the necessary pilot hospitals. After return of clarifications, the dataset was amended accordingly.

A small-scale analysis of the data took place using Stata 15 and aggregated national and hospital level results produced. Denominators, numerators, medians, standard deviations (SD) and lower and upper quartiles were generated from the data as appropriate to ensure it was fit for purpose and could be used to produce robust results and conclusions. The percentage of missing data was also provided for each data item to inform discussions on changes or removals from the datasets.

Pilot results

The AADP pilot storyboard (Figure 3.4) summaries the pilot process and results.

Figure 3.4 AADP pilot storyboard



In total, 34 pilot hospitals submitted the following:

- 292 adult clinical records
- 408 paediatric clinical records (264 1–5 years old, 144 6–18 years old)
- 29 adult organisational records
- 26 paediatric organisational records
- 30 individual submissions of feedback.

Figure 3.5 presents the pilot hospitals that registered and submitted data. Two hospitals, shown in purple, registered for the process, but did not submit data. Those presented with a circle registered as a trust and submitted data for more than one hospital.

Figure 3.5 Pilot hospitals who submitted data for the AADP pilot

Full aggregated national pilot results are available in appendices 27–31, but headline findings can be found below.

Although these results are for a small number of pilot hospitals and are not nationally transferable, they do help to highlight areas of good practice, as well as areas which require improvement.

For example, many asthma patients are being administered systemic steroids within the recommended timeframe of 1 hour following admission to hospital (median of 1–1.5 hours) and over half of all adult and paediatric hospitals are already using a formal discharge bundle. However, nearly a quarter of adults admitted to hospital are current smokers, with only approximately half of them having smoking cessation prescribed/discussed prior to discharge, and very few hospitals are carrying out patient and carer surveys to seek feedback on their services more than once a year.

Table 3.1 AADP pilot clinical audit headline results

Clinical audit results*	Adults % (n/N) or Median	Paed.1–5 % (n/N) or Median	Paed.6–18 % (n/N) or Median
Total denominator (number of records submitted)	**292**	**264**	**144**
Patient information			
Age *(median)*	41	3	9
Gender:			
• Male	25.3% (74/292)	72.6% (191/263)	59.7% (86/144)
• Female	74.7% (218/292)	27.4% (72/263)	40.3% (58/144)
Record of mental health diagnosis	20.9% (61/292)		1.4% (2/139)
Record of learning disability	1.4% (4/292)	1.9% (5/264)	2.2% (3/139)
Smoking status 'current smoker' *(adults only)*	28.1% (81/288)		
Acute presentation and admission			
PEF on arrival *(median based on 215 adult records and 17 paediatric 6–18 records)*	210		180
Sp02 on arrival *(median based on 215 adult records, 141 paediatric 6–18 records and 264 paediatric 1–5 records)*	96	95	95
Time to systemic steroids *(hours) (median)*	1.5		1.0
Steroids administered *(paed. 1–5 only)*		77.0% (198/257)	
Time to β2 agonists *(hours) (median)*	0.7	0.7	0.5
Length of stay			
Median *(hours)*	67.5	20.6	24.8
Review and discharge			
Discharge bundle used:			
• BTS bundle	26.0% (75/288)	8.2% (21/255)	18% (25/139)
• Non BTS bundle	34.0% (98/288)	45.1% (115/255)	40.3% (56/139)
Discharge bundle elements completed:			
• Inhaler technique	71.5% (188/263)	70.5% (170/241)	80.9% (106/131)
• Medication classes reviewed	70.5% (184/261)	66.2% (153/231)	70.9% (90/127)
• Doses reviewed	68.5% (178/260)	64.1% (143/223)	63.5% (80/126)
• Importance of adherence to preventer medication discussed	69.6% (179/257)	34.2% (75/219)	53.2% (67/126)
• PAAP modified	28.2% (55/195)	5.4% (11/203)	22.6% (24/106)
• PAAP issued	59.3% (137/231)	43.8% (98/224)	41.6% (47/113)
• Triggers documented	69.5% (178/256)	34.8% (81/233)	46.5% (59/127)
• If current smoker, smoking cessation discussed/prescribed	45.7% (79/173)		7.3% (7/96)
• Follow up request – community, within 2 days	57.3% (146/255)	41.6% (97/233)	30.2% (39/129)
• Follow up request – specialist, within 4 weeks	73% (195/267)	19.4% (43/222)	23.4% (29/124)

**Where the data item was left entirely blank, these hospitals were removed from the denominator.*

Table 3.2 AADP pilot organisational audit headline results

Organisational audit results*,**	Adults	Paediatrics
Admissions	***Median***	***Median***
Total number of asthma coded emergency admissions in 2016 *(median)*	326	181.5
Organisation of care	**% (n/N)**	**% (n/N)**
Designated, named clinical lead for asthma	82.8% (24/29)	72.7% (16/22)
Integrated care		
Number MDT meetings to discuss asthma patients	34.5% (10/29)	65.2% (15/23)
Patient and carer engagement		
Formal survey seeking patient and carer views on respiratory/paediatric services:		
• Continuous	0.0% (0/29)	40.9% (9/22)
• >4 times a year	3.4% (1/29	4.5% (1/22)
• 3–4 times a year	3.4% (1/29)	4.5% (1/22)
• 1–2 times a year	10.3% (3/29)	18.2% (4/22)
• Less than once a year	31.0% (9/29)	18.2% (4/22)
• Never	51.7% (15/29)	13.6% (3/22)
Hospital enables patients access to own healthcare records:		
• Yes	62.1% (18/29)	65.2% (15/23)
• No	34.5% (10/29)	21.7% (5/23)
• Not known	3.4% (1/29)	13.0% (3/23)
Transitional care		
The young person has a full record of their condition	50.0% (14/28)	65.2% (15/23)
Their GP has the same record	53.8% (14/26)	60.9% (14/23)
The young person has a transition plan and that they have worked on this with both paediatric and adult clinicians	42.3% (11/26)	43.5% (10/23)
The young person has a named case worker to assist in signposting for them and their family	24.0% (6/25)	34.8% (8/23)

** Data items chosen for organisational results are those completed by both adult and paediatric services.*

*** Where the data item was left entirely blank, these hospitals were removed from the denominator.*

Pilot feedback

Pilot feedback contained approximately 159 comments. These provided:

- clear indication of which data items, helpnotes and the rationale required refining or changing
- information on which data items were difficult to answer or the information difficult to obtain
- an indication on where validations did not work or were not appropriate
- information on where the bottlenecks in data collection may occur, eg the identification of patients using hospital record systems
- rationales for the removal of data items
- additional information with which to make any other necessary decisions on the datasets, eg the structure and order of the data items.

Both the adult and paediatric clinical datasets took a median time of 15 minutes to complete for each patient, which made it clear that further refinement would be needed to ensure that clinical burden is kept to a minimum and the goal for minutes per case is met and consistently achievable for all hospitals. Areas for potential exclusion include mental health and learning disability (as alternative sources for the data are available; see section 5) and the reduction/streamlining of the acute observation and treatment data items, such as PEF and oxygen, both of which are made up of multiple sub-items.

Positive comments about the datasets and their ease of use were received, an example of which is provided below.

> **Stephanie Smith**
> Clinical audit facilitator, Maidstone and Tunbridge Wells
> *'Once I was familiar with the database, it was quite easy to complete it from the paperwork supplied by the respiratory team.'*

Four case studies were submitted following the completion of the pilot. These provided examples of good practice and how hospitals incorporated the new audit process and datasets into their existing clinical practice and day to day working life. They are available in appendices 17–20 and hospitals should be encouraged to review these when planning their participation in the National Asthma Audit.

Pilot reporting

Pilot hospitals were provided with individualised spreadsheets with their aggregated hospital results for both the clinical and organisational audits benchmarked against the national pilot average. Hospitals were asked to discuss these and use them to identify areas of good practice and/or areas where potential improvements were needed.

3.2.5 Potential key indicators

In order to allow for real-time reporting capabilities in the design of the National Asthma Audit, work was carried out to identify key indicators of hospital asthma care which could be easily tracked over time. Using the pilot results, evidence from national asthma guidelines and standards and expert consultation, the following potential key indicators were identified:

- Smoking – number of current smokers and number receiving smoking cessation pharmacotherapy.
- Frequency with which peak expiratory flow (PEF) is taken upon arrival at hospital as a key objective measurement of the severity of the asthma exacerbations (PEF is not collected for pre-school children. It was agreed another measure should be sought for this cohort).
- Discharge bundle – the number of patients receiving all five elements of the recommended BTS discharge bundle as a composite measure (assessment of inhaler technique, assessment of medication and adherence, the review/issue of a personalised asthma action plan [PAAP], an assessment of triggers and exacerbating factors and requests for follow-up).
- Readmissions – the number of patients being re-admitted to hospital within 30 days following their initial admission.
- Feedback would be sought on interest around a key indicator on parity of esteem.

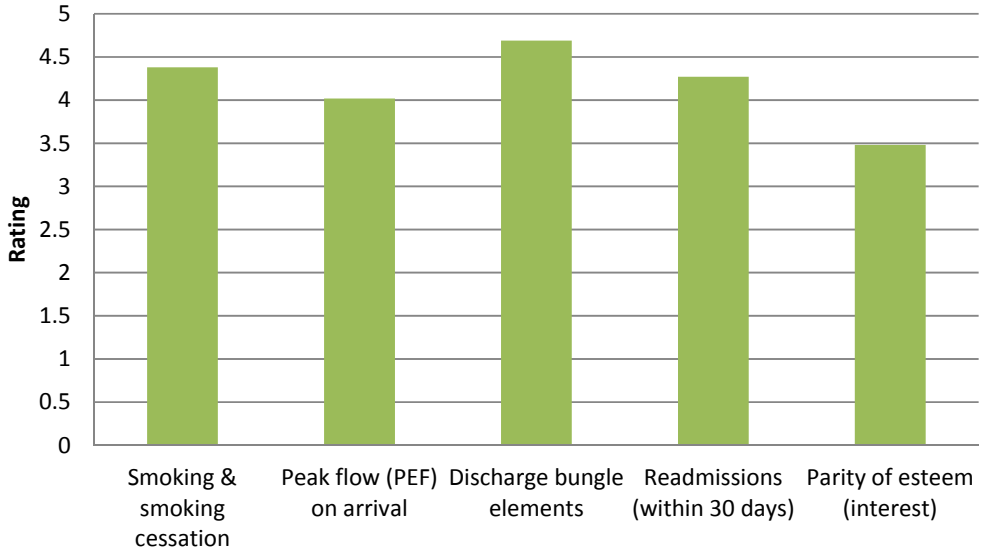
Although these general topics were put forward for feedback, the intention would be that separate adult and paediatric versions of these would be created, rather than one set of run-charts to fit all.

An online survey was produced and distributed to all pilot hospitals and necessary stakeholders in November 2017. This survey outlined the proposed key indicators, with their accompanying rationale and examples of real-time run charts to provide respondents with a visual example of how they would be used and measured. Hospitals were asked to rate how useful they would find each key indicator for quality improvement and service development purposes.

Key indicator survey results

48 responses were received in total (from the approximately 140 people approached). Figure 3.6 presents the results of the survey for each proposed key indicator.

Figure 3.6 Key indicator results



All four proposed key indicators scored an average of over 4 out of 5, meaning they were considered to be 'useful' or 'very useful'. Interest in parity of esteem was rated slightly lower.

Within the feedback to the survey there was a call to make the key indicators more paediatric-focused and general suggestions for additional or alternative key indicators including:

- time to initial treatment with systemic steroids *(would require case mix adjustment)*
- dose of prednisolone at initial review*
- self-management plan, of any form, on admission*
- spirometry*

** These topics are not included in the proposed clinical datasets. For the rationale for excluding data items see section 3.2.6 and/or appendix 13–16.*

To make the proposed key indicators more paediatric specific, the following could be considered for paediatric run-charts:

- if regularly exposed to second hand smoke at home, whether parents/guardians are offered smoking (cessation) advice (as an alternative to smoking and smoking cessation)
- Sp02, rather than peak flow, on arrival as this is appropriate for all children.

3.2.6 Patient views on emergency care

Patient and carers at the Focus Group were asked which elements of emergency care were most important to them and how acute exacerbations of asthma were treated. The quotes below provide detail on some of the responses received to this.

What's important to asthma patients and carers about their emergency hospital care?

Correct, timely treatment [obtainable from the secondary care clinical datasets]
'So, for me that's … I mean it's challenging. It's almost like it's a near miss really. So, they have been applying an incorrect treatment package for an emergency situation and they've not been quick enough to respond to those challenges...'

Review and discharge (Patient Focus Group report citation) [obtainable from the secondary care clinical datasets]
There was discussion in the group of the following being important to be included in the review at discharge:

- *Medication review*
- *Inhaler technique check*
- *Referral to a specialist consultant and access to correct treatment*

3.2.7 Final dataset content

As a result of the processes above the following five datasets were produced, with approximately 22 clinical (excluding identifiers) and 40 organisational data items:

- Paediatric clinical (1–5 years old)
- Paediatric clinical 6–18 years old)
- Paediatric organisational
- Adult clinical
- Adult organisational.

The datasets address the following areas of asthma care and organisation:
Clinical

- Patient demographics (age, gender etc)
- Pre-hospital care
- Acute observations and treatments
- Review and discharge processes.

Organisational

- Number of admissions
- Staffing levels, including unfilled posts
- Organisation of care (7-day working, access to designated leads)
- Management of care
- Integrated care
- Patient and carer engagement
- Transitional care

All final proposed datasets can be found in appendices 7–11.

3.2.8 Asthma and COPD Overlap (ACO) syndrome

The epidemiological evidence concerning the prevalence of ACOS patients is mixed (ranging from 4–40%) and depends very much upon the definitions used to either distinguish asthma from COPD, or to provide criteria for ACOS. It is also important to acknowledge that the concept of ACOS is not one that is particularly well known or understood among the non-respiratory clinical community.

As the asthma and COPD audits will be administered together, for the **adult secondary care** audits (ie both asthma and COPD), a pragmatic solution to the difficulty in defining patients should be adopted using the approach recommended in the literature, which is to manage each patient according to their **dominant phenotypical expression** at the time of admission. This would, therefore, highlight the need to consider the differential and overlap of diagnoses at the audit case entry point (via the webtool – see section 8 of this report), asking clinicians to define cases as:

1. asthma, to be entered into the asthma audit
2. COPD, to be entered into the COPD audit
3. ACOS with dominant asthma exacerbation, to be entered into the asthma audit
4. ACOS with dominant COPD exacerbation, to be entered into the COPD audit

For each case entered (into either COPD or asthma audits), a key variable recorded as part of the demographic/general admission information, will be to define which of the above categories the patient has been allocated to; a decision which will be made by the senior clinical decision maker on the admitting ward round. Providing these four diagnostic categories will also facilitate sub-group analyses at a later stage, and in particular if diagnostic overlap leads to confused management of patients.

Section 4: Development of primary care audit

4.1 Overview

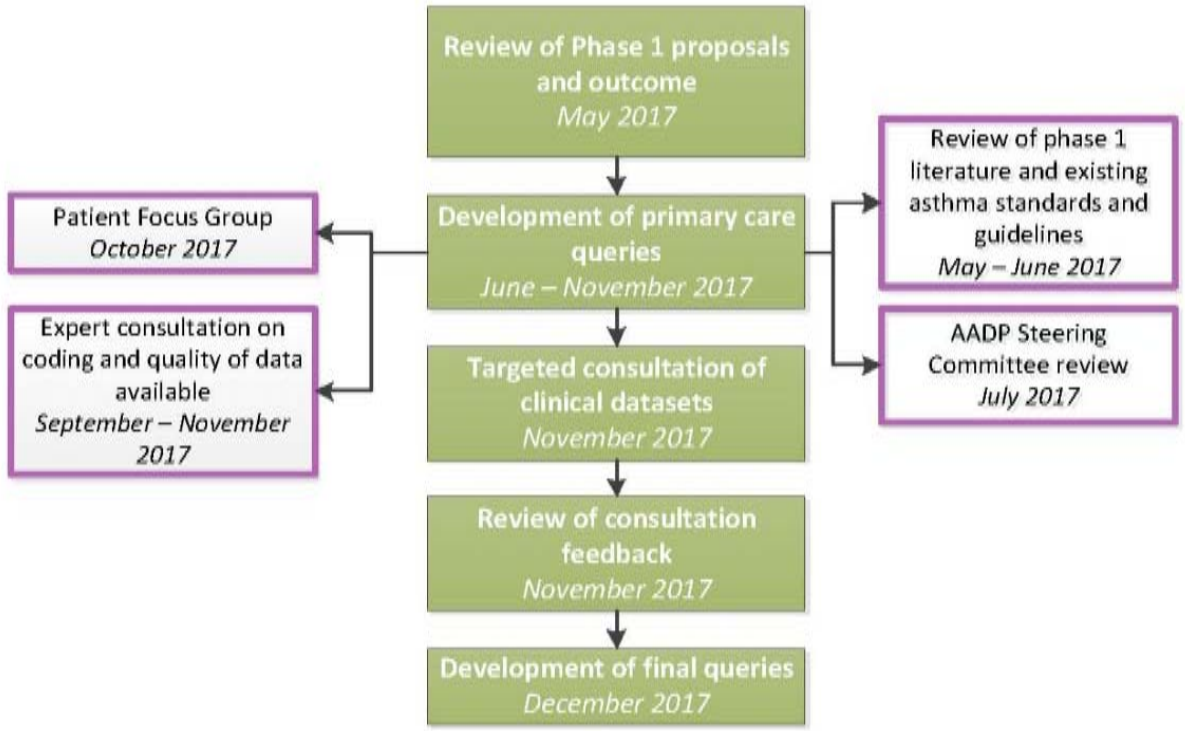
Final proposal from Phase 1 of the AADP

The statement below outlines the final proposal for the primary care component of the National Asthma Audit.

'It would be possible to capitalise on the National COPD Audit Programme experience of using primary care data from Wales, in order to provide some insights into a subset of primary care practices.'

Following the outcome of phase 1 and in order to meet the phase 2 objectives outlined in section 1, work was carried out to plan and develop a set of primary care queries around which the extraction of primary care data from GP practices in Wales would be based. Figure 3.1 provides an overview of this work.

Figure 4.1 Overview of primary care audit development



This section will outline the timescales and development activities undertaken to produce the primary care audit methodology and datasets. Using the results and information obtained from this work, comprehensive conclusions and recommendations will be provided.

4.2 Development of the primary care queries

Primary care is charged with the continuous monitoring and management of all asthma patients via routine annual reviews, follow-up after asthma exacerbations and prescribing of medication and treatment. Nationally, over 5 million asthma patients[2,3] require access to these services to ensure their asthma is managed in line with national guidance and standards and their risk of adverse outcome minimised. Approximately 260,000 of these patients reside in Wales.[17]

The National Review of Asthma Deaths (NRAD) reported that only 57% (111) of cases reviewed had evidence of routine primary care review in the year preceding death and identified potentially avoidable factors related to routine care, supervision and monitoring in primary care in 70% (137/195) of cases.[5]

With this in mind, the aim of the primary care audit process was to produce robust, clear queries which address key aspects of primary asthma care and provide robust results and lessons which are transferable to other nations.

4.2.1 Communication strategy

The communication strategy was developed with the following aims for primary care:

- to raise awareness of the AADP and forthcoming National Asthma Audit
- to ensure messages and information about the AADP were spread as broadly as possible
- to seek and communicate with participants for targeted consultation of the primary care queries.

4.2.2 Development methodology

A further exploration of asthma evidence, guidelines and standards took place in May 2017 to identify individual elements of recommended primary asthma care, in order to inform the content of the queries and address all areas of asthma care which had been identified as poor or variable in phase 1.[9] The new NICE guideline (NG80) on the diagnosis, monitoring and chronic asthma management was published in November 2017. Although this could not therefore be used during the initial developmental phases, it was reviewed upon publication for anything that may have a direct impact on the proposed content of the primary care queries.

Throughout June 2017, the information gained from this review was used to produce initial queries. These were then subject to several rigorous rounds of review, refinement and expert consultation. A significant part of this work involved seeking methodological guidance in order to understand if the draft queries corresponded to extractable Read codes (ie codes that both exist and are used in practice) and, if so, the quality of data that would be extracted, to ensure the query could be answered.

With the aim that the asthma and COPD national audits will be co-administered and extracted, the queries were mapped as closely as possible to those currently extracted by the National COPD Audit Programme. This would enable joint extraction to take place if required, and hence reduce the resource involved.

The process outlined above resulted in the identification of 13 queries which addressed several key areas of primary asthma care, including diagnosis, annual reviews, personalised asthma actions plans (PAAPs), smoking and asthma treatment and prescribing. Any queries considered but not included in the final list are provided in appendix 22, with the reason for non-inclusion.

4.2.3 Targeted consultation

In November 2017 a targeted consultation process was held. Key stakeholders, including the Association for Respiratory Nurse Specialists (ARNS), the Primary Care Respiratory Society (PCRS) and the Royal College of General Practitioners (RCGP), were approached and asked to identify two-to-three representatives who would be willing to participate in this process.

Once identified, these representatives were formally invited to take part and were sent all necessary information and materials in mid-November 2017. Responses and feedback were requested 7 calendar days later.

Ten responses (from the 13 people approached; details of respondents can be found in appendix 5), containing approximately 85 comments, were received to the targeted consultation. These contained:

- requests for further clarification on query parameters, wording used and methodology
- recommendations on how queries could be improved and provide more robust data
- suggestions for additional queries or query components
- ideas for other sources of data and information that may be of use, and
- information on where issues may arise.

This feedback highlighted where improvements and further streamlining needed to take place and provided an indication of where queries needed refining to ensure they provided the robust and comprehensive data required.

4.2.4 Patient views on routine primary care

During the Focus Group in October 2017, asthma patients and carers were asked what they felt were the most important aspects of routine primary care. The quotes and citations below provide detail on some of the responses received to this.

What's important to asthma patients and carers about their routine primary asthma care?

Diagnosis (FeNO testing) [obtainable from Primary Care queries]
'And so, we were referred to a consultant at X who said, I'm gonna deal with your allergies and your asthma because they're connected. And the first thing he did was do the nitric oxide testing and actually did a very proper diagnosis to his asthma'

Personalised Asthma Action Plans (PAAPs) [obtainable from Primary Care queries and secondary care clinical datasets]
'The creation of a plan. It all comes down to, for us, if we let it slip it will go and it can spiral out of control and I'll be in hospital in a week.'

Inhaler technique [obtainable from Primary Care queries and secondary care clinical datasets]
'But in reality nobody had ever in the last 20 years asked to see me using an inhaler and check that I am using it correctly. So, I think although it's a box ticking exercise, there is something about asking your GP practice "are you sure this person knows, have you actually checked while they have been with you"?'

4.2.5 Final query content

As a result of the processes above, 13 primary care queries addressing various areas of primary asthma care were identified. These queries covered the following areas:

- patient demographics (age, gender, ethnicity etc)
- comorbidities, including mental health and learning disabilities
- exacerbations of asthma in primary care
- diagnosis of asthma (via spirometry, peak flow and FeNO testing)
- Personalised Asthma Actions Plans (PAAPs)
- annual reviews
- inhaler technique checks
- RCP's 3 key questions*, ** [18]
- smoking status and exposure to second hand smoke
- prescription information (>3 courses of prednisolone, >12 short-acting beta agonist, long-acting beta agonist and inhaled corticosteroid and < 4 inhaled corticosteroid)

** Three key questions to assess asthma control. They include:*
Have you had difficulty sleeping because of your asthma symptoms (including cough)?
Have you had your usual asthma symptoms during the day (cough, wheeze, chest tightness or breathlessness)?
Has your asthma interfered with your usual activities (eg housework, work, school, etc)?
*** The Asthma Control Test (ACT) could be used as an alternative to this if necessary.*

4.3 Audit methodology

Due to there being over 2,000 GP practices in Wales,[19] audit methodologies that include approaching GP practices directly for individual patient information are not feasible or sustainable due to the time, resource and funding required.

Exploration of a primary care audit in Wales was included in the specification for the AADP as this is currently successfully undertaken by the National COPD Audit Programme, which extracts data directly from GP systems, using Read codes. This tried and tested method seems to be successful in providing accurate data, information and lessons which are nationally transferable, without making individual requests to practices for data. Transferability has been confirmed by small scale extractions done by clinical commissioning groups (CCGs) and GP practices in England and the, albeit informal, feedback received from this.

NHS Wales Informatics Service (NWIS)

NWIS is a public health service organisation which provides IT software services to users across NHS Wales and to other parts of the United Kingdom.

NWIS currently works with the National COPD Audit Programme to deliver the Welsh Primary Care audit[20] and coordinate the extraction of data. Primary care data is automatically extracted from practices that opt-in to the National COPD Audit Programme. These data are pseudonymised at source (ie no identifiable data leaves the practices that have opted-in), as follows:

- NHS number is replaced by study ID (a sequence of 10 letters and numbers)
- postcode is transformed to Lower layer Super Output Area (LSOA) and Welsh Index of Multiple Deprivation (WIMD)* index
- date of birth is transformed to patient age
- date of death (if recorded) is transformed to age at death.

** WIMD is designed to identify areas of Wales which are the most deprived. Deprivation scores are automatically computed for all LSOAs in Wales from home postcode as recorded by the general practice at the time of extraction. The WIMD uses eight types of deprivation domains to construct deprivation ranking. These are income, employment, health, education, access to services, community safety, physical environment and housing.*[21]

This removes the need for patient consent or section 251 application and approval processes, although approval is still required from the Welsh Data Quality System (DQS) Governance Group. The data is then transferred securely to the NWIS 'safe haven' central repository and, from there, securely transferred to the RCP and Imperial College London for analysis and reporting. Practice level reports, which support practices to access their own benchmarked data promoting quality improvement activities, are made available via the NWIS Primary Care portal.

It is recommended that the National Asthma Audit take the same approach. This will enable a single annual extraction of primary care data for both asthma and COPD, which will reduce resource and financial burden.

Section 5: Exploration of alternative data sources

Final proposal from Phase 1 of the AADP
It was proposed that further exploration of the following took place in phase 2:

- Prescribing/pharmacy datasets
- Ambulance datasets

Following the outcome of phase 1 and in order to meet the phase 2 objectives outlined in section 1, this section provides information on the exploration of prescribing/pharmacy and ambulance datasets, as well as other national datasets which may be used for the purpose of, and to compliment, the National Asthma Audit.

5.1 Secondary care data sources

5.1.1 Ambulance data

Until recently there has been an annual audit of asthma care provided by ambulance services carried out by the National Ambulance Service Clinical Quality Group (NASCQG). This audit included all English and Welsh ambulance services and assessed their performance against six asthma clinical performance indicators, including the delivery of an asthma care bundle. The last set of results was published in June 2016.[22]

In early 2017 the NASCQG audit was discontinued, meaning there is no longer national coverage and therefore potentially limited merit in any linkage. Local services may 'opt in' for future rounds, but any linkage is, therefore, likely to require data sharing agreements with each individual ambulance service and an unknown cost.

As a result of this, a pre-hospital section was added to the secondary care clinical datasets with the aim of providing some insight into the asthma care provided by ambulance services, as well as first responders and GP practices. The pre-hospital section was tested in September 2017 as part of the secondary care pilot process, the results of which can be found in appendices 27–31.

5.1.2 Hospital Episode Statistics (HES) and Patient Episode Database for Wales (PEDW)

Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions, outpatient appointments and A&E attendances at NHS hospitals in England.[23] Full datasets can be obtained from the HES data dictionary.[24]

The Patient Episode Database for Wales (PEDW) records all episodes of inpatient and day case activity in NHS Wales hospitals, including planned and emergency admissions, minor and major operations, and hospital stays for giving birth. Hospital activity for Welsh residents treated in other UK nations (primarily England) is also included.[25]

Section 251 and Data Access Requests (DARS) processes should be followed in order to obtain/link with HES and PEDW datasets. Further information on DARS can be found at the end of this section and details on information governance and section 251 processes can be found within section 6.

Admitted patient care

Bespoke linkage of patient level audit data with HES and PEDW admitted patient care (APC) data is routinely conducted by national audit programmes (eg Sentinel Stroke National Audit Programme [SSNAP] and the Falls and Fragility Fracture Audit Programme [FFFAP]).

The majority of information about the care received by patients admitted to hospital for acute exacerbations of asthma will need to be obtained on a prospective basis from hospitals due to the detail required (which is not included in the APC datasets). Therefore, for the purposes of a National Asthma Audit, the APC datasets would be used for:

- case ascertainment (surveillance of cases submitted vs cases coded as asthma by hospitals)
- pre and post-admission (tracking patients being admitted to hospital more frequently)
- exploration of comorbidities (looking at types and number of other associated conditions),
- parity of esteem (ensuring that physical and mental disabilities are treated equally)
- reducing clinical burden (ensuring that that data collection is not duplicated and that datasets are streamlined and within the recommended limits – see section 3.1).

HES APC data is made available in November of each year for the financial year prior, eg 2016/2017 data was made available in November 2017. 2016/17 APC data is also available from PEDW.

Emergency care

Respiratory conditions, including asthma, account for over 600,000 emergency care attendances each year.[26] This combined with the fact that emergency care departments collect and record data in many different ways, makes attempting to obtain information directly from them difficult. National audits such as the Clinical Audit of Moderate and Acute Severe Asthma have collected data directly from emergency care departments but for a sample of cases only (approximately 14,000).[15]

Emergency care treatment for those patients admitted to hospital will be captured via the continuous secondary care audit. Therefore, information on emergency care attendance would largely be used to provide insight into the outcomes of asthma patients who had been admitted to hospital and subsequently re-presented at emergency care departments (without being re-admitted to hospital). Additionally, it could be used to provide insight into patients who are attending emergency care repeatedly and are then admitted to hospital.

The Royal College of Emergency Medicine (RCEM) is currently undertaking a review to revise coding data for emergency care and provide consistency in the way that it is reported.[27]

This new dataset will use Systematised Nomenclature of Medicine Clinical Terms (SNOMED CT) codes and provide improved clarification of the chief complaint and diagnosis (including codes specific to asthma), as well as treatments, investigations and referrals. Further information can be obtained by the NHS England webpages.[28]

PEDW also has an Emergency Care dataset details of which can be accessed via the NHS Wales data dictionary.

The new ECDS for England will be available via NHS Digital from mid-2018 and will replace the existing HES A&E dataset, which will be switched off at some point in 2019. Until this date the A&E dataset will remain and continue to be available. Both the England and Wales data are available via the Data Access Request (DARS) system.

Outpatient care

There are approximately 1.5 million outpatient appointments for respiratory conditions, including asthma, per year.[29] There are audit programmes, such as the National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis,[30] which collect information directly from outpatient services, but via trust leads and, currently, on a recruitment (consent) basis and for a much smaller cohort (around 40,000 per annum). Approaching outpatient departments directly for hundreds of thousands of records would be resource-heavy and unsustainable.

HES and PEDW both have outpatient datasets, which could be used to provide insight into the outcomes of asthma patients who have been admitted to hospital and subsequently attend outpatient appointments. However, unlike the emergency care datasets, the outpatient datasets coding only contains information on the speciality (eg respiratory) the patient was seen by, rather that the reason for attendance. This problem is compounded by the fact that asthma patients may be seen in geriatric and paediatric clinics. A diagnosis field (populated using ICD-10 codes) is available; however, this is not completed accurately as there are no differential charges for common outpatient attendances.

This unfortunately means that it is not possible to establish if the care and treatment given during each outpatient appointment was specifically for asthma and if the care meets existing standards and guidelines.

5.1.3 Office for National Statistics (ONS)

The Office for National Statistics (ONS) mortality data contains information related to all deaths registered in England and Wales. ONS mortality data can be linked with audit data in order to carry out analyses on 30 and 90 day mortality post discharge (asthma deaths are identified using ICD-10 codes – J45-46), as well as inpatient mortality rates.

There is currently a lag time of three weeks on ONS data requested through the Data Access Request (DARS) system (further information below). However, for the purposes of a National Asthma Audit, annual reporting on mortality, as per the approach taken by the National COPD Audit Programme and SSNAP, is recommended as it reduces the cost and resource involved, provides meaningful data, and also provides hospitals with time to review, implement change and the result of that change to take effect.

5.1.4 Data Access Requests (DARS)

In order to link audit data with HES and ONS data, a data access request must first be made to NHS Digital. NHS Digital (previously Health and Social Care Information Centre [HSCIC]) provides national information, data and IT systems for health and care services. They act as an internal NHS IT provider which holds a wide variety of health and care service data for which national audit programmes and researchers etc. can make requests for healthcare improvement activities.[31]

Data access requests must be made for all new and renewed requests for HES and ONS data. Information required in order to make these requests includes:

- the location of the data
- whether the request is new, an extension, a renewal or an amendment
- what datasets are required (eg HES APC, mortality)
- what service is being requested (eg bespoke linkage)
- the frequency of the data required
- the purpose for which it will be used for.

Further information, including the application process, costs and how additional information can be sought can be found on the NHS Digital webpages.[32]

5.2 Pharmacy data sources

Many standards and guidelines around asthma care and management relate to the correct prescription and review of pharmacological treatments. Adherence to asthma medication is directly related to asthma control and therefore requires continuous monitoring to ensure control is maintained. Being able to track and review prescriptions for asthma medication being processed directly through pharmacies could potentially open an additional avenue by which adherence to medications can be monitored.

5.2.1 Community Pharmacies

Community Pharmacies (UK) Ltd works in partnership with GP practices, establishing and operating health centre based pharmacies providing pharmacy services at the point of care.[33]

Phase 1 of the AADP explored this as a potential source of pharmacy data. It was established that no diagnosis information or patient identifiers were held within Community Pharmacies' dispensing records. Without these, the ability to link data and draw useable conclusions is very limited.

5.2.2 ePACT2

ePACT2 is an online application which gives authorised users access to 60 months of prescription data, real-time online analyses of prescribing data, 6 weeks after the dispensing month, held on NHS Prescription Services' database and provides more functionality then the previous ePACT.[34]

Despite this, ePACT2 does not hold any patient information and therefore no linkage is possible.

5.2.3 NHS Business Services Authority – Prescription Information Services (England)

NHS Prescription Services calculates the remuneration and reimbursement due to dispensing contractors across England.[35] It is mandatory for all dispensing contractors in England to submit information about all prescriptions dispensed to prescription information services and they therefore hold a very comprehensive prescribing dataset which includes the following:

- NHS number
- Date of birth
- Age
- Prescriber
- General practitioner
- Drug
- Strength
- Quantity

Five years of prescribing data is currently held by the service, with identifiers being available from April 2015. This means that the National Asthma Audit would be able use this dataset to link to for information on prescriptions dispensed for a patient pre-and post an admission to hospital.

Information on diagnosis is not available; therefore a caveat would be required alongside the data stating that there could not be certainty that the prescription was for asthma, rather than another respiratory condition.

5.2.4 NHS Wales Shared Services Partnership – Primary Care Services

Primary Care Services is a division of the NHS Wales Shared Services Partnership.
It provides contract management, reimbursement, post payment verification and information services for GPs, community pharmacies, dentists, opticians and appliance contractors who provide services to the NHS in Wales.

Primary Care Services captures a wide range of data on the provision of NHS services, including pharmacy and prescribing information.[36]

At the moment these datasets do not include patient identifiers, meaning that there is no linkage capability. However, the Primary Care Services prescribing information team are currently looking into how approval can be obtain to collect patient information, meaning there may be the possibility of linkages in the future, although an exact time period was not available.

5.2.5 Medicines Use Review and Pharmacy Quality Payments (England and Wales)

Medicines Use Reviews (MURs) are a part of the Advanced Services of the community pharmacy contract. It involves the pharmacist conducting a structured review with patients about their medicines use. The aims of this service are to improve patients' knowledge, concordance and use of medicines.[37]

The Quality Payments Scheme has been introduced by The Department of Health (DoH) as part of the Community Pharmacy Contractual Framework in 2017/18. This involves payments being made to community pharmacy contractors meeting certain gateway and quality criteria. Criteria include:

- provision of at least one specified Advanced Service
- the provider's NHS Choices entry being up to date
- the provider having the ability for staff to send and receive NHSmail
- ongoing utilisation of the Electronic Prescription Service.[38]

These were explored as potential sources of pharmacy data within phase 1 of the AADP. Datasets were found not to be standardised and would provide insufficient detail, as each person could obtain or redeem prescriptions from multiple different pharmacies. It would not, therefore, be possible to draw firm conclusions on adherence to medication or an individual's asthma control.

5.2.6 PrescQIPP (England and Wales)

PrescQIPP is an NHS funded not-for-profit organisation that supports quality prescribing for patients throughout the NHS. It helps to ensure that treatments prescribed to patients are safe, effective and good value for money. They do this by providing information, guidance and support on prescribing to a large community of NHS professionals and a platform to share innovation, learning and good practice.[39]

Due to very little information being publically available, no further details could be obtained on PrescQIPP.

5.2.7 Patient views of other areas of asthma care

During the Focus Group other areas of importance to asthma patients and carers were highlighted. The quotes and citations below outlined some of these.

What other things are important to asthma patients and carers about asthma care?

Parity of Esteem [obtainable from linkage to HES APC dataset]
'…But also at the other end of the scale, if you are moving in to an area where you've got patients who are suffering from dementia or any … it's a hugely risky area for people. So, if you are under the care of somebody and you're not necessarily able to control or express the same kind of warning signs that maybe everyone on the table would consider obvious today, wind the clock forward a few years. You're in a care home, okay, and you're starting to struggle with your breathing. Would somebody else spot that? How does somebody else baseline that?'

'But actually national things give a really wide overview. And my feeling was that perhaps on this edition you'd drill down in to people … they'd drill down to people with mental health or learning difficulties and that maybe the next one will drill down in to a different area.'

Equity of care (Focus Group Report Citation) [obtainable from linkage to HES APC dataset]
The importance of looking at different groups in the population separately, particularly for children
This was a common theme throughout the group and almost all participants mentioned its importance in some way. Groups mentioned as important to look at in isolation were children, teenagers, older people with dementia, people with mental health conditions and/or learning difficulties and people for whom English is not their first language.

Section 6: Information on patient reported outcome and experience

Final proposal from Phase 1 of the AADP

It was proposed that further exploration of the following took place in phase 2:

- PROMs/PREMs

6.1 Patient reported outcome and experience measures (PROMS and PREMS)

Patient reported outcome or experience measures, known as PROMS or PREMS, assess the quality of care and healthcare outcomes from the patient's perspective. PROMS measure the patient's health, or health related quality of life, at a single point in time, whereas PREMS measure the patient's perception of their healthcare experience. Both are often collected through short questionnaires.[40]

Not only do PROMS and PREMS offer a unique insight into the patient perspective, they also enable comparison between good care according to national standards and guidelines (ie hospitals that perform well/badly according to key indicators) and good care according to the patient.

6.1.1 Asthma UK: Annual survey

Aim and content

Asthma UK carries out an annual survey during the summer of each year. This survey is specifically designed for asthma patients and aims to gain insight into patient perspective of asthma management and care and fill any knowledge gaps on specific topics.

It includes both static questions (asthma in general, recent experiences of primary, specialist and emergency care), which are included every year and are used to portray changes over time, and questions around an annually changing 'focus' topic. Annual focus topics address areas such as prescriptions and triggers and are predominantly used to update Asthma UKs knowledge and information. The latest Asthma UK Annual Survey is available from Asthma UK's website.[41]

Participation and coverage

The 2016 annual survey was completed by approximately 6,000 people. Participants from each of the UK devolved nations are included, but in 2017 there has been an additional recruitment drive to gain better representation from Wales and Northern Ireland.

Results are currently reported at national, country and regional level. The survey has previously requested patient postcode in order to drill down further locally but this was discontinued due to data protection issues.

Dissemination pathways

Awareness of the survey and the invitation to participate is disseminated via two main communication streams:

- Asthma UK's membership and internal communication channels (newsletters, website etc), which provide regular contact and awareness raising opportunities with existing members
- Paid-for, targeted social media adverts which have been adopted in order to broaden the surveys reach and increase its participation rates.

Potential for PREMS source for National Asthma Audit

During Phase 1 of the Asthma Audit Development Project (AADP) an initial discussion was held with Asthma UK to establish if:

a) the results from their annual survey could be used as a proxy over time for PREMS
b) there was potential for the survey questions to be adapted/added to in order to create links between the survey and the areas covered or highlighted by the proposed Asthma Audit.

Following this discussion it was agreed that there was potential for this to be explored in more detail in Phase 2. A meeting to discuss this further was organised and held in August 2017. At the meeting it was agreed that there is potential for the questions to be adapted or added to, especially if themes arose from the audit findings, and it would be useful to explore these further from a patient point of view. However, the survey involves a considerable investment of time and resource and therefore there is limited potential for co-creation and joint working. It was recommended that strong evidence towards the adaptation or adding of questions would need to be submitted with all requests. These requests would also need to be reviewed and agreed by the Asthma UK management team prior to their inclusion. No guarantee of the changes being incorporated could be made.

There would be potential for contributing financially to the survey. These contributions could be used to supplement advertising costs, which may increase the reach and participation of the survey and provide the additional resource required to facilitate co-creation and working. The successful bidder of the National Asthma Audit would be able to approach Asthma UK with an idea of desired increase in scale of participation, with Asthma UK providing estimates on what financial contribution would be required to reach these levels. If participation was increased significantly, there would be potential for further regional reporting and investigation.

6.1.2 Friends and Family test

The Friends and Family test is a feedback tool which supports the principle that people who use NHS services should have the opportunity to provide feedback on their experience. Based on the responses, services are scored based on the percentage of respondents who would or would not recommend their service to their friends and family. It was created to help service providers and commissioners understand whether patients are happy with the service provided, or where improvements are needed. Since 2013, 30 million pieces of patient feedback have been submitted and the test has been rolled out across most NHS services.[42,43]

Results of the survey are made publically available every month via the NHS England website[44] and are available at a variety of levels (national overview, inpatient, ambulance, community etc). Within the individual service type files (inpatient, ambulance etc) results are broken down further by region, trust, site, ward and first and second speciality.

For the purposes of a national audit programme, the monthly data releases of this data could be combined and the hospital and department results amalgamated to provide an overall score matching that of the necessary audit period. However, although this may provide some insight into patients' experience of the service, the information provided is of a low discriminative value. The questions asked are simple and do not allow for further exploration of the quality of care or the full experience of the patient.

6.1.3 National PROMS programme (NHS England)

The National PROMS programme is commissioned and has its strategic direction set by NHS England (since 2009). It currently covers four clinical procedures:

- hip replacements
- knee replacements
- groin hernia
- varicose veins.

The PROMS calculate the health gains after surgical treatment. This health status information is collected before and after a procedure and provides an indication of the outcomes or quality of care delivered to NHS patients.[45]

Exploration of this in phase 1 of the AADP found that although there could be potential for asthma to be included in the National PROMS programme, this would most likely be a long term option, with it ultimately sitting completely separately to the National Asthma Audit.

6.1.4 PROMS, PREMS and Effectiveness Programme (PPEP)

A programme of work, funded by the Efficiency Through Technology Fund (ETTF), has been established to progress the collection of patient reporting outcome and experience measures across NHS Wales via an electronic platform compatible with existing Health Board data systems.[46]

PPEP will collect generic PROMs, and disease-specific PROMs in selected conditions. Working with the Respiratory Health Implementation Group (RHIG), the programme is in the process of selecting a COPD-specific tool for addition to the platform in 2018. Further work is also being undertaken to develop tools specific to adult and paediatric asthma.

There is the possibility that, once established, this work could be integrated into the joint COPD and asthma audit programme and used as a proxy for PROMs and PREMs in Wales. Liaison with PPEP and further exploration is recommended.

6.1.5 Bespoke national PROM/PREM audit

There is the possibility that a bespoke PROMs/PREMs audit, which would collect patient outcome and experience measures from COPD and asthma patients, could potentially be run by the successful provider of the audit programme.

The National Diabetes Inpatient Audit encompasses a similar patient experience component by which eligible inpatients who are able and willing are asked to complete a questionnaire prior to their discharge from hospital. Once complete, hospital staff collect and submit this information to the National Diabetes Audit (NDA), where it is cleaned and analysed. Their 2016 report is available via the NHS Digital webpages.[47]

An alternative to this paper based methodology is to host a specific PROMS/PREMS area on the audit webtool, which patients could access to complete an online questionnaire.

For both of the above, consideration would need to be taken of the following:

- whether it would be useful enough to identify the patient only by the hospital they were admitted to, or if the measures reported would require linking to a specific person (eg a unique ID for both the paper-based and online questionnaire; which would link the PROM/PREM to the secondary admission record) in order for a comparison to be made; this would also require consideration of the information governance requirements needed to do this
- how many patients would be needed to make this exercise valuable (ie case ascertainment issues)
- the additional resource involved, particularly with option 1, and the potential clinical burden associated with this
- the funding required to produce a continuous paper-based system or online system
- the additional communication mechanisms around promoting and reporting this.

6.1.6 Patient views on information from the National Asthma Audit

How would asthma patients and carers like information from the audit to be communicated to them?

Patient level report (Focus Group Report Citation)
The majority of participants expressed positivity towards a patient-focused report but stressed the need for it to have a clear purpose, with meaningful sections or editions for underrepresented groups like children and people with mental health conditions.

Infographics (Focus Group Report Citation)
Almost all participants gave a positive response to the infographic page, but the importance of all information being relevant to the audience was strongly expressed.

Section 7: Information Governance

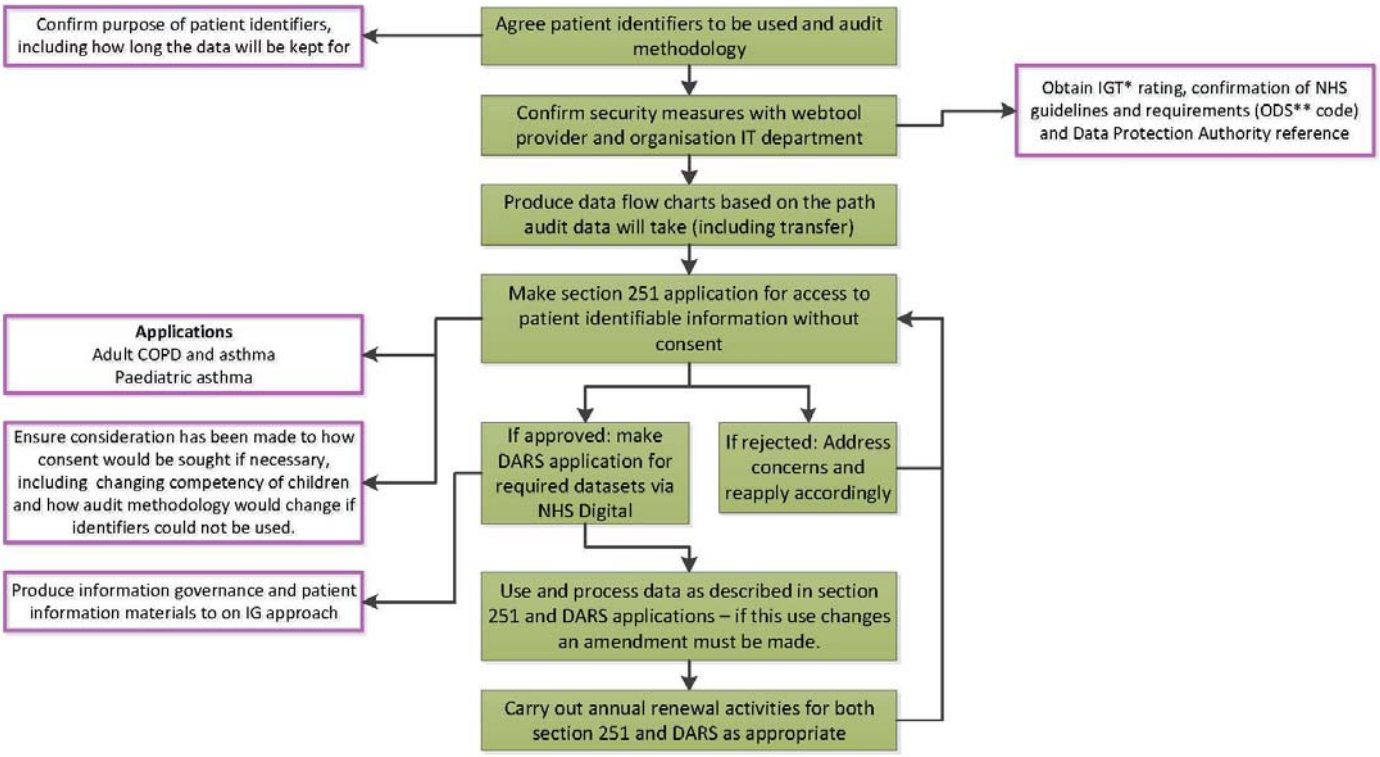
Information governance refers to the legal framework governing the use of personal confidential data in health care. The law allows personal data to be shared between those offering care to patients but it protects patients' confidentiality when data about them are used for other purposes. These 'secondary uses' include:

- reviewing and improving the quality of care provided
- researching what treatments work best
- commissioning clinical services
- planning public health services

Generally speaking, people within the healthcare system using data for secondary purposes must only use data that does not identify patients unless the patient has provided explicit written consent for the particular activity to take place.[48]

In planning a national audit approach (as per the AADP phase 2 objectives), consideration must be made to the legal framework that an audit programme must be delivered within. This section outlines what that should be. With the proposal that the national asthma and COPD audit programmes be co-administered, this section addresses a joint information governance approach, a summary of which is below.

Figure 7.1 Summary of information governance approach



**Information Governance Toolkit (IGT)*

***Organisation Data Service (ODS)*

7.1 Patient identifiable information

Patient identifiable information (NHS number, name, date of birth, postcode and date of death) is used by many national audit programmes and enables:

- linkage with external national datasets such as HES admitted patient care, A&E and outpatients, parity of esteem and ONS mortality data
- investigation into socioeconomic and deprivation patterns.

More than one item is collected as a triangulation mechanism (ie to make sure the data pertains to the right patient in the event that some fields are missing).

The organisation contracted to take on the joint national asthma and COPD audit programme should ensure that:

- a specific reason for each collecting identifiable item can be provided
- appropriate security measures will be taken to ensure their confidentiality
- data retention schedules are made explicit.

Further details on the purpose of each patient identifier proposed for the National Asthma Audit can be found within the rationale of the proposed datasets in appendices 7–11.

7.1.1 Data flows and charts

Data flows track the flow of data from submission, storage, processing and reporting, including third party applications, and show who has access to what type of data at what point in the audit process.

The proposed data flow charts for the primary and the secondary care (adult and paediatric) components of the National Asthma Audit have been mapped out and can be found in appendices 23–25.

As the COPD and asthma audit programmes will be administered together, ensuring that data flows, where possible, are the same as the existing accepted and approved COPD audit methodologies, it will aid the section 251 and DARS application processes. With regard to Welsh primary care data extraction, if asthma data is pseudonymised at source as with the current National COPD Audit Programme it will remove the requirement for section 251 approval entirely.

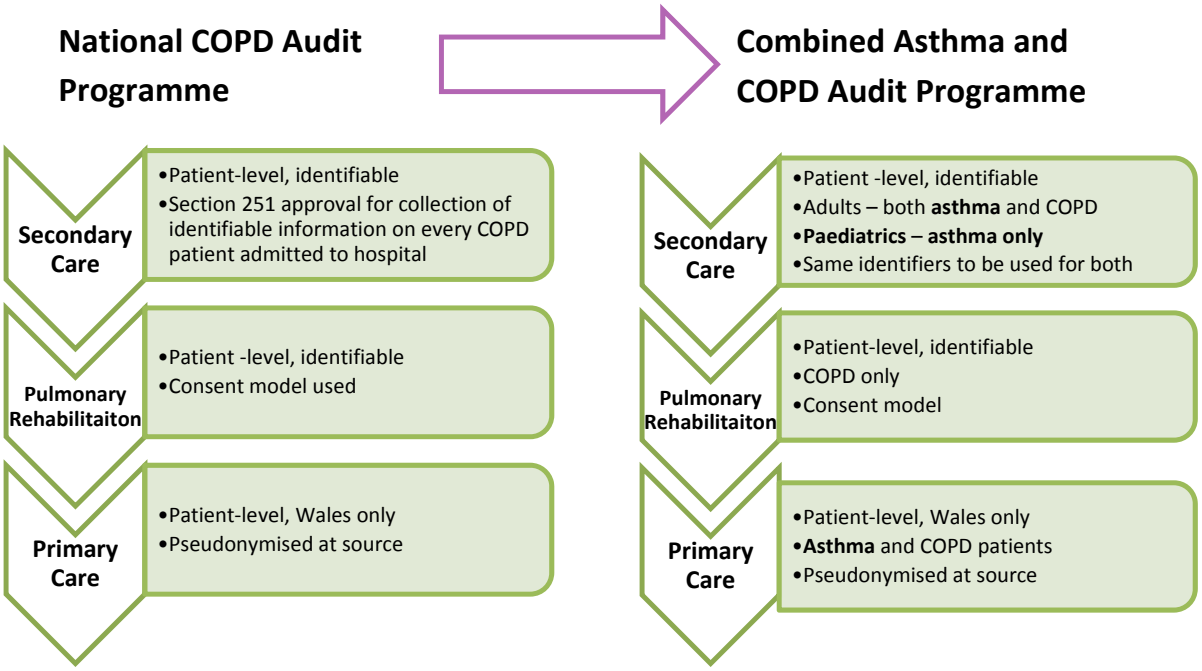
7.2 Section 251 and the Confidential Advisory Group (CAG) process

Section 251 enables the common law duty of confidentiality to be overridden for medical purposes, where it is not possible to use anonymised information and where seeking consent is not practical.[49] This is in place as it is recognised that there are essential activities within the NHS where obtaining consent from patients to use their identifiable information is impractical or not possible. Reasons might include high patient volumes (for example there are 60,000 hospital admissions due to asthma every year), and/or issues with patient acuity (which would affect their capacity to give consent) at the point the data is collected. Section 251 is, therefore, in place for most national audit programmes, including the National COPD Audit Programme, the Sentinel Stroke National Audit Programme (SSNAP) and the Falls and Fragility Fracture Audit Programme (FFFAP).

In July 2017 the Asthma Audit Development Project (AADP) team met with the Health Research Authority (HRA) advice team. This meeting was to seek advice on and discuss the section 251 requirements and Confidential Advisory Group (CAG) processes for a new National Asthma Audit, which would be jointly administered with the existing National COPD Audit Programme. The discussion was had in this context to ensure the provider of the combined Asthma and COPD Audit would be fully informed about key information governance issues upon commencement of the new audit programme in 2018.

Figure 7.2 outlines the overview given to the HRA advice team of the existing National COPD Audit Programme and the incorporation of the proposed National Asthma Audit.

Figure 7.2: Overview of current National COPD Audit and proposed NACAP



7.2.1 Section 251 application for the new asthma audit

In summary, the 'ideal' would be to complete and submit three separate applications for the secondary care element of the programme – COPD, asthma adult and asthma paediatric. This would mean renewals and amendments could be made to individual elements with ease and without potential changes to other components of the workstream. However, if the applicant feels it is appropriate, and can provide suitable evidence and support for this, the adult COPD and asthma components could be combined into one application.

Individual applications for each audit component (three applications)

If the choice is made to submit three separate applications (ie for each audit component), due to their very similar purposes, identifiers and data flows, the applications for COPD and asthma adult could be largely the same. This will assist with helping to reduce the workload associated with completing multiple applications. However, any differences between the two components should be made very clear.

In addition, the COPD application should reference the historic National COPD Audit Programme section 251 approval. This will enable the CAG team to easily track between applications during review and consideration.

Combined adult (COPD and asthma) applications

If the provider of the new programme feels it is appropriate and sufficient evidence can be provided, the secondary care COPD and asthma adult applications could be combined. Again this will help to reduce burden and resource required and reference to the existing National COPD Audit Programme approval should be made wherever possible.

If the current provider of the National COPD Audit Programme is successful in a bid for the combined audit, existing support would stand (subject to normal annual renewal processes) for the secondary care COPD audit. This existing application could then be amended to include the secondary care asthma adult audit and no new application would be needed. This application could not, however, include the secondary care asthma paediatric component; a separate application *must* be made for this.

Paediatrics

Although the identifiers requested for the paediatric component of the audit would be the same as for the adult audits, additional considerations need to be made within the paediatric application. The applicant should consider and actively address what would happen once a child becomes competent (around 13 years of age) and how, if necessary, consent would be sought from parents and/or children. Plans should be outlined on what information would be made available about the project, whether this would cover a range of reading ages, and how information about the project would be distributed to this cohort.

Consent

Each application should provide solid evidence as to why seeking consent from these patients would not be practical and what the requested identifiers will be used for.

Information on making and renewing section 251 applications can be found via the Health Research Authority website.[50]

Information on information governance approach

Information governance and patient information sheets should be produced and made easily available. These should provide information about the programme and information governance approach for the benefit of healthcare services, professionals, patients and the general public. Information on information governance should cover:

- the audits approval to collect patient identifiable information
- what hospitals are required to do for the audit
- information about data flows
- who has access to data (both patient-identifiable and non-patient-identifiable)
- how data is transferred between different sources
- where and how data is stored
- how long data will be kept for (retention period).

7.3 National Data Opt-Out and General Data Protection Regulation (GDPR)

On 25 May 2018 the new General Data Protection Regulation (GDPR) and National Data Opt-Out Programme will take effect in England, with the former also effecting Wales.

7.3.1 National Data Opt-Out Programme (England only)

All patients accessing NHS (health and social care) services in England will be given the opportunity to opt out of having their personal confidential information used for purposes outside of direct care. These purposes are commonly referred to as planning and research, and include data submitted/requested and processed by national audit programmes. The opt-out overrides section 251 approvals but does not apply to anonymised datasets (where the patient cannot be identified). Further information can be obtained from the NHS Digital webpages.[51]

The potential impact on the National Asthma Audit is:

- the requirement of hospitals to uphold this opt-out preference (increased clinical burden)
- the increased likelihood of patient records being excluded from both the data submitted by hospitals and the NHS digital (HES and ONS) datasets (there are currently approximately 1.2 million type 2 objections[52])
- as a direct result of the above point, the increased likelihood of mismatch between the secondary care audit and NHS digital datasets (the inability to obtain patient outcomes etc).

Although it will not be the responsibility of the audit programme to uphold these preferences, it should:

- for the secondary care audit, provide hospitals with guidance and support to ensure they are able to do so
- for the primary care audit, identify and use the correct Read codes are used to ensure data for patients who have opted out are not extracted.

7.3.2 General Data Protection Regulation (GDPR)

This is a regulation intended to strengthen and unify data protection for all individuals in the European Union (EU). It aims to give control back to citizens and residents over their personal data and requires organisations to be more explicit and transparent about the legal basis by and reason for which they hold, use and process personal data. Further information on this can be obtained via the Information Commissioners Office (ICO) webpages.[53]

These both affect the use of personal confidential information and need to be considered in the planning of a National Asthma Audit and the Information Governance approach that it takes.

Section 8: IT requirements and development

Many national audit programmes now choose to have online webtools on a secure centralised platform, which offer:

- secure data collection, validation, import and export facilities for NHS service providers
- national, local, service and real-time reporting capabilities
- access to information and resources quickly and easily for a wide variety of stakeholders, including patients and the general public.

As it has been proposed that the COPD and asthma audits be administered together, the webtool would need to be able to provide all necessary features for both COPD and asthma audits, as well as the robust security measures that are required of such a platform.

In June 2017, a meeting was held with an IT expert who develops and hosts webtools for national audit programmes to understand the implications of future IT development of the audit.

8.1 Audit webtool specification

8.1.1 High level structure of the webtool

The structure of the audit webtool would need to allow easy identification and navigation of the relevant audit areas. Figures 8.1 and 8.2 provide examples of potential layouts for the combined webtool.

Figure 8.1 Combined asthma and COPD audit webtool structure: Example 1

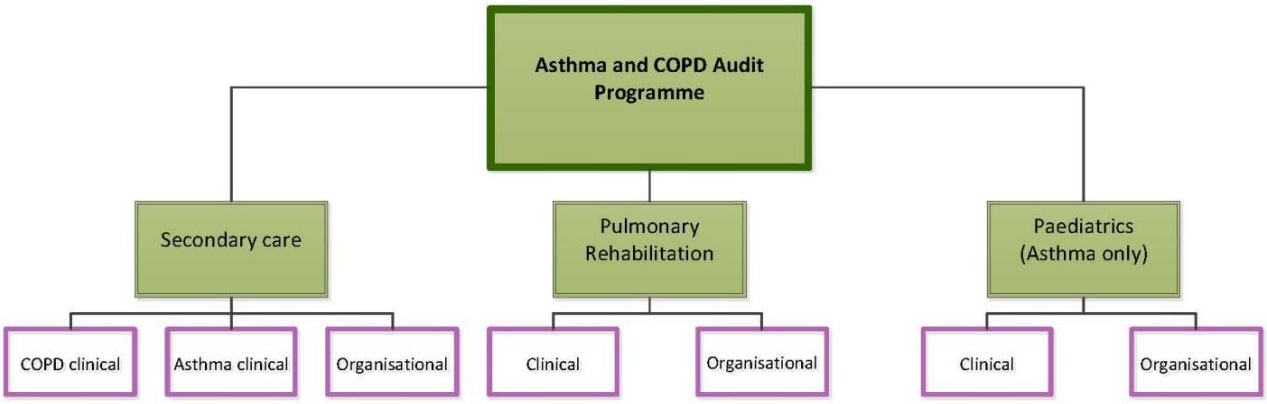
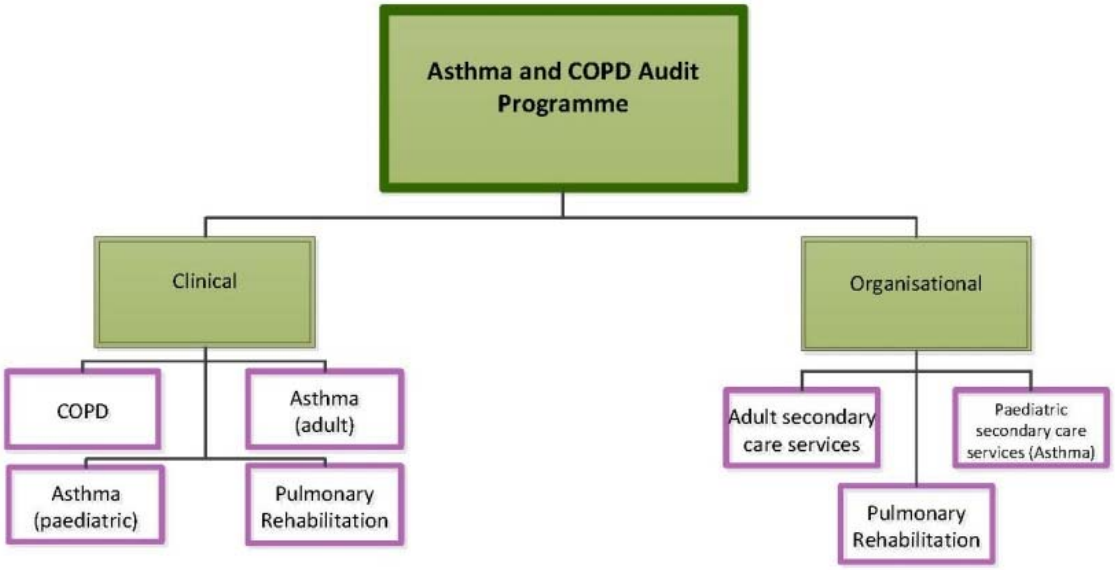


Figure 8.2 Combined asthma and COPD audit webtool structure: Example 2



Both these proposed structures were presented to the IT expert who raised no concerns. However, it was noted that Figure 8.1 would afford the opportunity for:

- the structure of pulmonary rehabilitation data collection area to remain the same as it currently is, providing some consistency
- a clear pathway for entering adult patients and whether they are being included in the asthma or COPD audit.

8.1.2 Security

Webtool provider

The webtool provider would need to have and be able to provide evidence of:

- the Information Governance Toolkit (IGT) rating of the appropriate level,
- confirmation of NHS guidelines and requirements being met (ODS code)
- a Data Protection Authority reference
- a data information protection policy
- an information governance policy
- a service level security policy
- assurance that data held by them is stored, processed and encrypted within a secure data centre which operates to ISO 27001 certification (2015).

This ensures that they are able to provide the security and have the authorisation necessary to host a webtool which collects and stores patient identifiable information, allow appropriate team members to access patient identifiable information, and transfer patient data when required by the audit programme (please refer to appendices 23–25, which cover data flow charts).

Participants and audit team access

The webtool would need to provide the ability for complex individual user profile permissions for both participants and the audit team. Participants should be able to register for particular services

and collect and see data and reporting outputs for their services only. Authorisation systems would need to be in place, enabling nominated service leads to authorise users. This ensures no one gains inappropriate access to service datasets or information.

The audit team would need access to all areas of the webtool and the ability to amend permissions, alter or create profiles and export user, service and audit information, but should not be able to see any of the patient identifiers.

There should be flagging systems in place to highlight where user profiles are not used and to facilitate the identification of participants who are no longer active or working for a particular service but may still have access to their information.

8.1.3 Information store and source

The webtool would need to be a source and store of information, including:

Back end

- user details: name, job title, role (clinical lead, data inputter etc), service(s), permissions
- service details: location, address, authorised users

Front end

- information and resources (including patient and public information)
- datasets and helpnotes
- audit dates and deadlines
- service level reports (available via permissions set)
- published reports and tools.

8.1.4 Audit data collection areas and datasets

Audit data collections areas would be needed to cover all audit components described in Figures 7.1 and 7.2. The clinical areas would need to be designed and developed for continuous audit and have the ability to recognise and flag duplicate entries (using unique identifiers such as NHS number and date of birth in combination with data of admission, etc). Both clinical and organisational data collection areas should:

- enable users to save and close records as and when needed
- provide functionalities such as record tracking and export to enable services and the audit team to review record status and carry out tailored chasing activities.

The online datasets should facilitate quick and easy data entry with consistent layouts for data items and answers and easy access to helpnotes for each item. They would require robust and comprehensive validation rules to ensure no illogical data could be entered, aiding data entry and reducing data cleaning requirements. For example, date of death cannot be before date of admission, or if a ‘parent’ data item is ‘No’ any sub-items should be greyed out.

Other audit programmes, including the National COPD Audit, also enable users and services to identify and add ‘custom fields’ which they can collect as part of their data entry process but are unique to them, require internal analysis and are not included in national or service level reports. This facility recognises that some services will require collection of information outside of the audit datasets and enables them to do this easily, without having to set up internal databases.

8.1.5 Reporting and data import and export

The webtool would need to allow access to both service level and public reporting outputs, in addition to real-time reporting features, if the National COPD Audit model of reporting is to be followed for consistency. Each set of reporting outputs would need a designated area of the webtool which is easily identifiable and navigable.

Service level reports and real-time reporting outputs would need to be made available as per the permissions set for each user (ie they should only have access to service reports they are authorised for).

In addition, services must have the ability to bulk import and export their data (via or into excel CSV) between reporting periods. Import capabilities in particular are important as they provide participating services with the ability to export data directly from their own systems into the audit webtool, via an approved CSV file which acts as a bridge. They remove the need to enter data for each individual patient and, therefore, can reduce clinical burden and transcriptional error. Data export enables services to access their own data for review and discussion with team members, managers and commissioners.

8.2 Timescales and planning for development

Development of the webtool should start as soon as possible following the initiation of the audit (proposed to be March 2018). The plan for its development should include individual deliverables for the webtool developer to ensure all requirements and works are carried out as needed, including:

- a procurement process to identify and contract a webtool developer, if necessary
- design and build
- internal (audit team and webtool developers) and external testing
- a pilot of the formal audit
- the correction and re-test of any ‘snags’ identified during testing and pilot.

8.3 Website

Webpages providing information about the audit programme and sign-posting to the webtool and all relevant reports and resources should be developed and made available for the general public.

Section 9: Conclusions and recommendations for next steps

9.1 Asthma Audit Development Project (AADP): phase 2 objectives

(See section 1 for original detail)

The following specific objectives were set for phase 2 of the AADP:

- design and deliver the phase 2 activity described in the selected option of the phase 1 appraisal
- produce a report to HQIP on the work undertaken.

9.1.1 Conclusions

These objectives have been met with:

- the planning, design, development and testing of secondary and primary care National Asthma Audit components as outlined by the final proposal in phase 1 of the AADP
- the exploration of other data sources, the legal framework within which the audit must be delivered and IT requirements required for its set up and maintenance
- the production of this final report which outlines the work undertaken, conclusions drawn from the project activities and recommendations for next steps.

9.2 Patient involvement

(See section 2 for original detail)

9.2.1 Conclusions

Patient involvement in the National Asthma Audit

Patient involvement in a national audit programme is essential and ensures the patient voice is embedded throughout. The programme governance structure should include patient representatives and, if possible, a patient and public involvement (PPI) group established to provide ongoing and consistent patient engagement.

What is important to asthma patients and their carers

The patient focus group held in October 2017 established that the following were key areas of importance to asthma patients and their carers:

- routine asthma care (annual reviews, inhaler technique, triggers)
- an awareness of different patient groups (age, gender, comorbidities)
- ensuring that a correct assessment of asthma severity could be made
- ensuring that appropriate and timely treatment were given
- clear, concise and consistent patient-friendly audit outputs to inform patient choice and increase awareness of care that should be received and patient/carer ability to campaign for better care.

9.2.2 Recommendations for next steps

1. Patient representatives should be identified and embedded into the audit governance structure; this should include a PPI group if possible.
2. The areas of asthma care identified by the Patient Focus Group as of most importance should be considered and included in the content and structure of the National Asthma Audit.

9.3 Development of secondary care audits

(See section 3 for original detail)

9.3.2 Conclusions

A secondary care audit of asthma care and organisation is deliverable and hospitals are able to incorporate the audit into their existing clinical practice and processes.

Methodology

The proposed continuous clinical audit methodology was practical and enabled collection of the data from across the asthma care pathway as per the hospital's needs, ie prospectively as the patient travels through the hospitals pathway, or retrospectively once they have been discharged.

Feedback and case studies identified potential delays with identifying patients eligible for inclusion, but many hospitals confirmed this issue would lessen once the audit process was embedded in day-to-day practice.

The methodology for a biennial snapshot organisational audit was also deemed practical, although some concerns were raised about the resource required to obtain the data. However, as this approach mirrors the methodology used by many other national audit programmes, participants were aware that the awareness raising and notice period given ahead would alleviate this during the actual audit.

Datasets

Hospitals confirmed that collecting the clinical and organisational information required was achievable.

Both adult and paediatric clinical datasets took a median time of 15 minutes to complete. National data, incorporating measures of variability (IQR, median, SD etc), can be produced from the datasets and used to define asthma care during hospital admission, discharge processes and follow-up. The clinical datasets and pilot results have also aided the identification of key indicators which can be used for real-time reporting and tracking improvements in key aspects of asthma care over time.

This is equally true of the organisational dataset. Time to complete was not recorded for the organisational datasets as, with it being a biennial audit, less resource would be required to complete it. However, as this was raised as an issue during piloting it is recommended that work take place to streamline the dataset and reduce the resource and time involved. Again, national data with measures of variability can be produced and used to depict asthma service structure and organisation.

Data from both the clinical and organisational datasets was therefore considered fit for purpose and appropriate to result in the audit being used to drive up the quality of asthma care.

Integration with the National COPD Audit Programme

Proposed audit methodologies match those of the current National COPD Audit Programme (continuous clinical audit and biennial snapshot organisational audit) and therefore ensures that adult service participants are already familiar with the process and can implement it quickly, and that adult and paediatric services can participate consistently across the new joint audit programme. Keeping methodologies the same will also enable recognition of and insight into Asthma COPD Overlap Syndrome (ACOS) by asking hospitals to following a specific data entry path and definition for each patient.

It is possible for the organisational audit for adult asthma and COPD to be combined and run as one, reducing clinical burden and audit resource. It is also possible to adapt the data items to make them paediatric-specific, enabling services to be measured and compared accurately and consistently (where possible).

9.3.2 Recommendations for next steps

1. That clinical datasets are subject to continued streamlining, with an aim for completion of 5–10 minutes, to reduce clinical burden further. As additional time may have been required to complete the pilot Excel data templates, time to complete should be re-tested once the audit webtool has been fully developed.
2. That organisational datasets are also subject to refinement and streamlining activities to reduce the time and resource required to complete them.
3. Work around integration with the COPD component of the joint audit should continue as this may lead to efficiency gains and further reduce clinical burden.
4. To build a robust webtool, with sound and effective validations to ensure that the risk of missing or illogical data is reduced and to house both the clinical and organisational datasets enabling online data entry and efficient data reporting.

9.4 Development of primary care audit

(See section 4 for original detail)

9.4.1 Conclusions

Methodology

Extracting primary patient care data directly from practices in Wales, using Read codes (SNOMED CT once in place), is a practical way of obtaining primary care information and gaining insight into that area of the patient care pathway. Using data pseudonymised at source removes the need for section 251 application and approval processes. This approach has been successful for the National COPD Audit Programme in providing accurate data, information and lessons which are nationally transferable.

Queries

The primary care queries outlined in appendix 21 have been confirmed as robust, comprehensive and covering key areas of asthma care and management by a variety of primary care stakeholders. They can be mapped to existing Read codes and the quality of data provided from them will be high.

Integration with the National COPD Audit Programme

The proposed methodology and queries are designed to aid easy integration into the existing National COPD Audit Programme approach and facilitate joint administration and extraction.

9.4.2 Recommendations for next steps

1. Identify SNOMED CT translation for the Read codes for each query in preparation for the transfer over to this coding system in May 2018.
2. Work around integration with the COPD component of the combined audit continues in order to ensure the extraction process for both components is robust, efficient and facilitates joint extraction of asthma and COPD to reduce resource and cost.
3. Carry out extensive liaison with NWIS around the extraction of asthma data in addition to COPD.
4. Joint extraction of asthma and COPD data enables investigation of Asthma COPD Overlap (ACO); therefore, exploration should take place as to how data is analysed for patients with both asthma and COPD.

9.5 Exploration of alternative data sources

(See section 5 for original detail)

9.5.1 Conclusions

Some national data sources exist which could be used to compliment the National Asthma Audit. These would predominantly provide information on patient outcomes. More specifically, the following datasets are likely to be of considerable value for the reasons outlined:

HES APC dataset

- case ascertainment (surveillance of cases submitted vs cases coded as asthma by hospitals)
- pre and post-admission (tracking patients who are being admitted to hospital more frequently)
- exploration of comorbidities (looking at types and number of other conditions)
- parity of esteem (ensuring that physical and mental disabilities are treated equally)
- reducing clinical burden (ensuring that that data collection is not duplicated and that datasets are kept streamlined and within the recommended limits [see section 3.2]).

Emergency Care Data Set (ECDS)

- patient outcomes – readmission proxy (frequency of attendance at emergency care due to asthma post admission, treatment received etc).

ONS mortality dataset

- patient outcome and mortality rates (30 and 90 day).

NHS Business Authority – Prescription Information Services

- dispensed prescriptions for individual patients pre and post admission to hospital.

Existing ambulance and outpatient attendance do not currently provide national coverage or contain the necessary information to enable their use.

9.5.2 Recommendations for next steps

1. Each of the datasets outlined above should be considered and their use planned for by the National Asthma Audit.
2. Continue to review status of currently unusable (eg ambulance, HES outpatient and pharmacy) datasets. If status changes, consider incorporation.

9.6 Information on patient reported outcomes and experiences

(See section 6 for original detail)

9.6.1 Conclusions

Patient Reported Outcome and Experience Measures (PROMS and PREMS)

There are several potential sources of PROMS and PREMS data which could provide insight into the patient perspective of their care and outcome. These include:

- Asthma UK annual survey
- Friends and Family test
- PROMs, PREMS and Effectiveness Programme (PPEP), Wales.

The National PROMS programme (NHS England) could additionally be considered, but as a long term option only as this currently does not include asthma.

Consideration could also be given to the successful provider developing a bespoke national PROMS/PREMS audit (for asthma and COPD), similar to the approach used by the National Diabetes Inpatient Audit. This would require thought around potential changes to information governance, cost and resource, and webtool development if done via an online questionnaire.

Integration with the National COPD Audit Programme

There are several opportunities for joint asthma and COPD patient engagement. These include:

- having asthma and COPD patients, or those with Asthma COPD Overlap Syndrome (ACOS), on a PPI group
- using data from PPEP, Friends and Family test and a bespoke PROMs/PREMs audit covering both asthma and COPD.

9.6.2 Recommendations for next steps

1. Continue to liaise with Asthma UK and PPEP around how their existing data could be used and integrated into the audit.
2. Carry out a pilot using the Friends and Family test data in order to provide some insight into its usability and the conclusions which could be drawn from it.
3. Explore webtool development, and the costs and resources required to develop a bespoke national PROMS/PREMS audit.

9.7 Information Governance

(See section 7 for original detail)

9.7.1 Conclusions

The information governance approach used by the joint COPD and asthma audit should include:

- a list of patient identifiers required for the audit, and confirmation of their purpose and retention period
- the confirmation of security measures and the necessary information obtained from the webtool provider and data processes organisation IT department
- the production of data flow charts
- section 251 and DARS application and approval processes, including consideration as to whether seeking consent is practical
- the production of information sheets on the information governance approach taken by the audit
- the annual renewal processes required by section 251 and DARS as appropriate.

Integration with the National COPD Audit Programme

Combined information governance arrangements are possible, particularly around adult asthma and COPD section 251 applications.

9.7.2 Recommendations for next steps

1. Work around integration with the COPD component of the combined audit should continue to ensure that, where possible, joint information governance arrangements are made to reduce cost and resource.
2. Investigate how the Information Governance approach for the National Asthma Audit will be affected by the National Data Opt-Out (England only) and the new General Data Protection Regulation (GDPR) and provide the information and support necessary in all Information Governance materials.

9.8 IT requirements and development

(See section 8 for original detail)

9.8.1 Conclusions

An online web-based platform should be developed for the joint asthma and COPD audit programme. This webtool will provide all necessary stakeholders and stakeholder organisations with access to the materials, facilities and information they require from the audit, including:

- easy access to information and resources
- data entry, validation and export facilities for users and services
- access to service level and national reporting outputs, as per the permissions required.

It is imperative that the webtool include the necessary security measures to ensure that service level and patient information is stored, used and processed securely and as per specific requirements which should be outlined in the information governance information for the audit.

Integration with the National COPD Audit Programme

The proposed joint webtool structures (Figures 8.1 and 8.2) enable easy identification and navigation of webtool areas, including the existing National COPD Audit Programme components.

9.8.2 Recommendations for next steps

1. Webtool development deliverables are identified and outlined within a formal document.
2. A webtool developer is identified and the requirements (using the deliverables as a basis for this) agreed.

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If you would like to join our mailing list and be kept informed of updates and developments in the National Asthma and COPD Audit Programme, please send your email address and contact details to the asthma email address given.

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