

*AAC Asthma Biologics RUP*

# Understanding opportunities to improve Severe Asthma Care in England

A National Benchmarking Exercise

*Summary report*

# Executive Summary

- As part of the [Accelerated Access Collaborative Asthma Biologics programme](#) a benchmarking exercise was conducted to assess the variation in severe asthma pathways and practices across England.
- The exercise was led by the [AHSN network](#), and in addition to the gathering insight into the challenges being faced in delivering severe asthma care, the exercise also brought together system stakeholders involved in asthma care and helped start discussions around where improvements could be made.
- The exercise looked to assess variation across the pathway, identify barriers to accessing severe asthma care and asthma biologics and also aimed to identify initiatives that are driving great clinical practice and patient care.
- All 15 AHSNs across the network engaged in the exercise working with stakeholders from organisations across their geography. Responses were received from 220 different organisations in England, either providing or commissioning asthma care.
- Analysis of responses identified 3 key areas for discussion focused on patient identification issues; resource constraints and capacity limitations. This short report aims to share the key insight gathered from the exercise.



# Executive Summary

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## Patient Identification

Patients with uncontrolled asthma, particularly those at risk from the devastating effects of oral steroids on mental and physical health, should be under the care of a specialist asthma clinician. Their early identification and referral is a critical step to minimizing harm, optimising outcomes and diagnosing severe asthma.

### Benchmarking Findings

- Processes for identification of people with difficult-to-control asthma in primary care were varied. In most cases, they were reactive (e.g. after an exacerbation or at annual review) rather than proactively using the patients history as a guide to future risk.
- Over half of primary care respondents also reported not having participated in training or education around severe asthma and its recognition.
- Specialist asthma centres (SACs) see referrals from a range of sources, although the primary referral sources for most (68%) were acute hospitals or from GPs located in close proximity to severe asthma centres.



## Resource

To ensure an efficient and effective pathway for people with asthma, dedicated resource is critical. This review found significant inequalities in what was available at system level, within regions and nationally.

### Benchmarking Findings

- Primary care respondents reported a general lack of funding for clinicians to support asthma care.
- 25% of responding Acute Trusts (secondary care) did not have a dedicated asthma clinic.
- Despite adherence assessment and support being a key component of asthma care, over 30% of SACs reported an absence of a designated adherence lead.
- Respondents from 9 SACs reported poor access to essential psychology support, a mandatory part of the severe asthma multi-disciplinary team (MDT).
- Over two thirds (68%) of responding SACs reported staffing limitations (i.e. medical staff, specialist nurses and pharmacist resource) as the most significant service barrier in the context of improving patient access.



## Capacity

Service capacity for SACs and their networked sites remains a significant constraint to improving access to severe asthma care and in turn biologic therapies.

### Benchmarking Findings

- Respondents from 7 SACs reported capacity challenges not linked to clinical staffing levels. Capacity was reported as being limited by infrastructure (physical space available for clinics and testing) and access to support (administrative support and supportive technology to improve access to data).

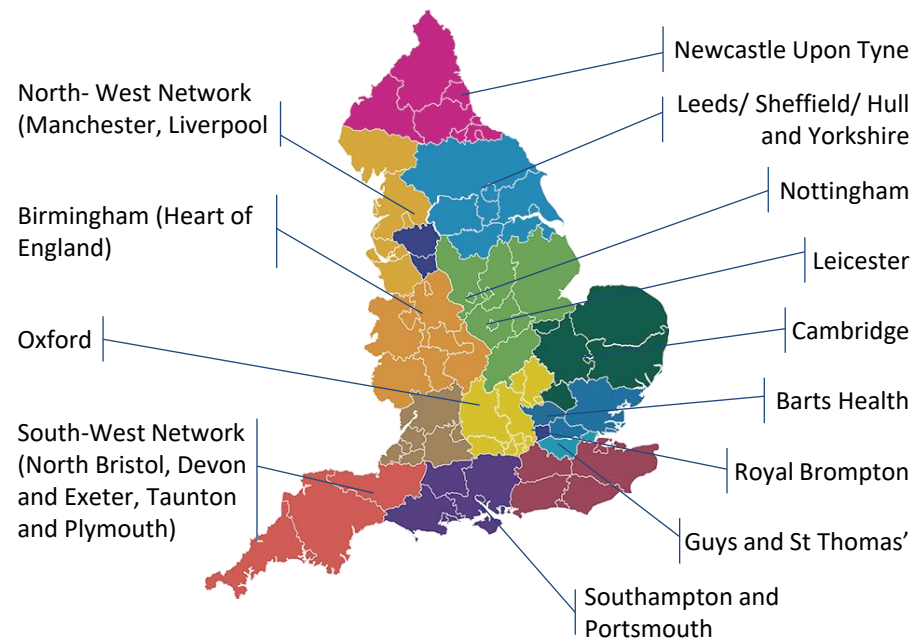
### Why is this important?

Limited resource and capacity is, and will continue to be, a significant barrier to accessing specialist asthma care. The findings reported show the scale of the challenge in meeting current and future demand for these services. It will be important moving forward that provision for Severe Asthma care is seen as a priority. Future changes in pathways and the commissioning landscape offer an opportunity to rethink delivery of care and to ensure these barriers do not continue to impede patient access.

# Background

- Asthma Biologics were selected as part of the Accelerated Access Collaborative (AAC) Rapid Uptake Products programme (RUP) in September 2020.
- The estimated eligible population for asthma biologics is 47,300 with only around 10,000 patients currently able to access these advanced therapies (17 -21%).
- This programme covers four high-cost biologic treatments approved for patients with Severe Asthma. These treatments are, Reslizumab, Benralizumab, Mepolizumab and Omalizumab. A fifth product Dupilumab is currently under NICE review.
- The aim of the Asthma Biologics programme is to improve patient care and outcomes by reducing inequalities and improving access to biologics for patients with severe asthma.
- As part of the scoping work for the programme, a benchmarking exercise was conducted to assess the variation in severe asthma pathways and practices across England.

## *Overview of Severe Asthma Centres (SAC) and network sites delivering severe asthma care in England*



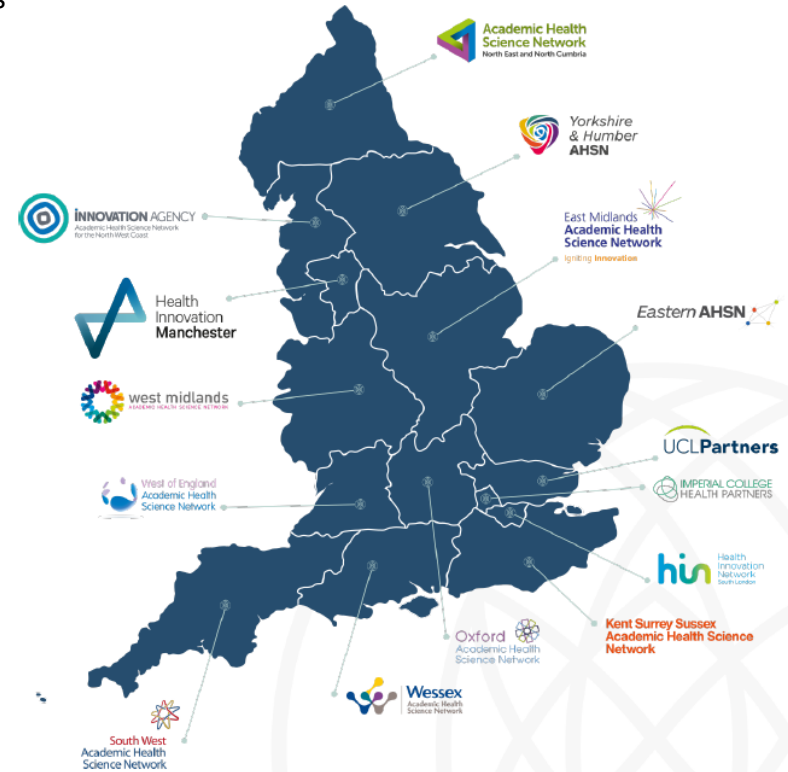
# Approach

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- The benchmarking exercise was based on a set of semi-structured interviews conducted with representatives from organisations involved in asthma care across England.
- Areas of benchmarking were agreed by the AAC Asthma Biologics programme team including clinical leaders involved in severe asthma care.
- Leads from all 15 AHSNs gathered insight from organisations in their regions including Severe Asthma Centres; Acute Trusts; Primary care sites and commissioning organisations.
- Responses were collated into a data comparison dashboard and analysis of responses was carried out by Oxford AHSN with support from KSS AHSN.
- Variation across AHSN regions relating to pathways, practice and care was shared with the relevant AHSN leads through the dashboard.
- The analysis provided in this report looks to provide an overview of the opportunities for improvement nationally, that would support enhancing severe asthma care and access to biologics.

## Overview of AHSN boundaries



# Response rates

- There was an exceptional response rate to the benchmarking exercise nationally with 220 individual organisational responses captured across different care settings.
- Engagement and response rates in each AHSN varied largely depending on pre-existing levels of engagement and also capacity for local stakeholders to engage

	Number of Responding Organisations	Estimated coverage nationally*
Severe Asthma Centres (and networked sites)	19	100%
Acute Trusts	73	60%
Primary Care Practice	65	49%** (0.9% of total GP practices across England)
Primary Care Commissioning	63	48%

\* Coverage reported by the number of organisations responding as a percentage of the total number of organisations nationally

\*\* For primary care and commissioning respondents, AHSN leads were asked to consult at least 1 commissioner and healthcare professional from a GP practice in each CCG footprint (135 CCG regions in total at the time of data collection although During the period between February - June 21 some CCGs have merged)

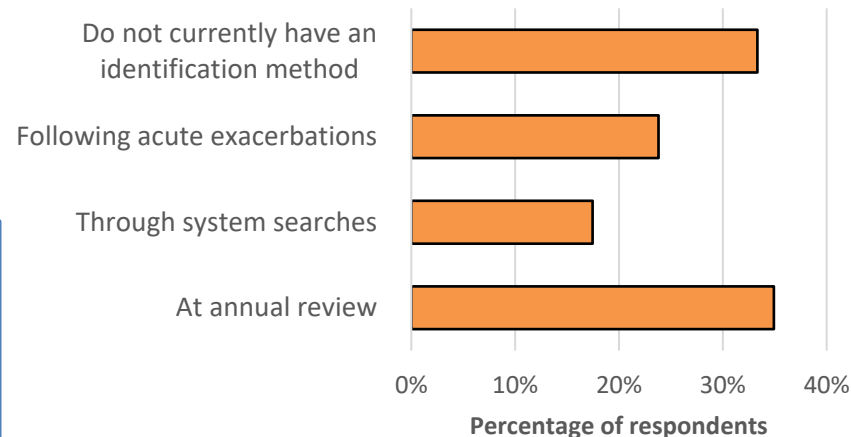
# Key Finding 1: Over a third of practices reported not having a method to identify high risk patients

- Whilst the exercise did not look to capture explicitly the proportion of practices with identification protocols in place, these data signal that of those sites that do attempt to identify, the most common approach would be to assess: at review, post-hospitalisation and to a lesser extent proactively through the use of system searches.
- Respondents also shared additional detail and alternatives approaches outside of those named:
  - Patients being picked up based on ACT scores and/or symptoms
  - Patients picked up by HCPs concerned about patients' asthma control
  - Patients being captured through the use of registers (High SABA; OCS use)

## Why is this important?

- [A recent review of primary care databases](#) (OPCRD) showed about 8% of Asthma patients in primary care have potentially severe asthma; of these less than 30% were referred to or known to secondary care. This demonstrates the importance of proactive identification initiatives in primary care.
- These data signify a significant opportunity to improve the severe asthma pathway through appropriate proactive identification of severe asthma patients.

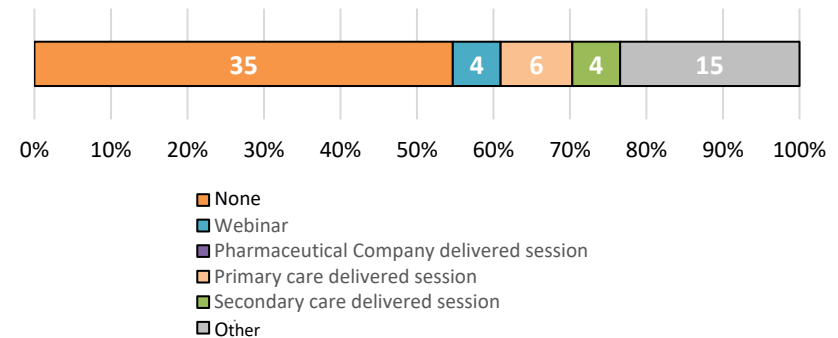
Approaches used for identifying potential severe asthma patients who may benefit from biologics (n=63)



## Key Finding 2: Over half of primary care respondents reported not having participated any severe asthma education

- Over half of respondents had never received any education on potential severe asthma management.
- Those respondents who did report participation in educational sessions, reported the use of webinars, and HCP delivered educational sessions from both primary and secondary care.
- Some respondents also shared a range of other formats in which they had learnt about severe asthma.
  - Advanced asthma education via CEPN web-based training
  - Meetings on severe asthma management through local networks
  - Competency-based learning through regional Respiratory Academics
- When the same respondents were asked how they would like to receive training in the future a number of similar themes emerged.
  - PCN level and system level approaches
  - Secondary/ Tertiary care leadership
  - Focussed session on aspects most important to primary care
  - Mix of digital and face to face where possible

Types of severe asthma education that primary care respondents had previously participated in (n=64)



### Why is this important?

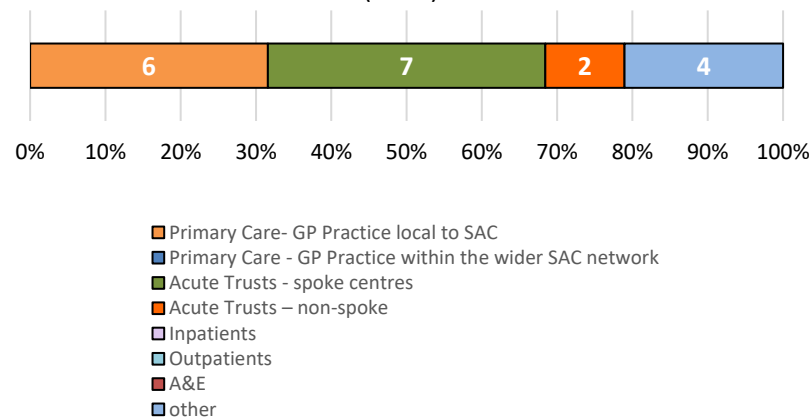
- Primary care awareness of uncontrolled and severe asthma will be key to identifying, optimising and where appropriate referring patients to secondary and tertiary services.
- There is a significant opportunity to improve education and awareness of severe asthma across those involved in asthma care in primary care



## Key Finding 3: Most referrals came from acute spoke sites or primary care sites *local* to the SAC

- Over a third of respondents said that inwards referrals to the SAC would primarily come from acute spoke centres, with only slightly less sharing that primary care sites local to the SAC would be the primary source of referrals.
- 4 respondents said “Other”, these included: a combination of Local GP referrals, regional hospital referrals and A&E, where no obvious primary source could be identified.
- No responses described primary care centres in wider networks as being a main source or referrals.

Primary sources of referrals to Severe Asthma Centres  
(n=19)



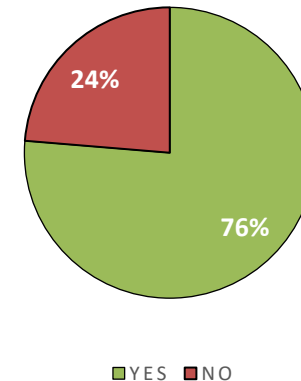
### Why is this important?

- Addressing health inequalities is a key ambition of the [NHS long term plan](#), and a key focus for the [AAC Asthma Biologics programme](#).
- Whilst it is not unreasonable that the “primary” sources of referrals are from primary and secondary care sites local to the SAC, these data support previous analyses <https://www.respiratoryoutcomes.co.uk/> which have shown patterns of referrals being concentrated from sites *local* to the SAC.
- To address this, ICSs and PCNs will need to have greater awareness of severe asthma and regional services, and pathways across geographies will need to be improved to ensure patients distal to SACs are not disadvantaged.

## Key Finding 4: Almost 25% of responding Acute Trusts reported that they currently did not have dedicated asthma clinic

- Whilst the population sizes will vary, an average Trust serving a population of 400,000 people, is likely to serve around 19,000 patients with asthma. Despite this it was uncovered in this work that from the 73 acute Trusts surveyed almost 25% did not have a dedicated asthma clinic in place.
- Although over 75% of acute Trusts responding have an asthma clinic service only just over half (56%) reported the provision of an asthma MDT in the Trust.
- It was encouraging to see that over 40% of Acute Trusts surveyed also reported providing some level of support for local GPs, although the nature of the support varied.

Percentage of Acute Trusts reporting a dedicated asthma clinic

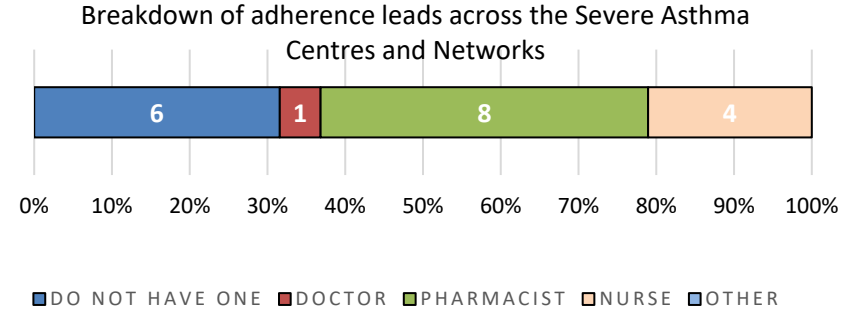


### Why is this important?

- In looking at the future of severe asthma pathways it will be important to take into account the variation in service provision and capacity. The variation described has the potential to introduce [health inequalities](#), and thus it will be critical for systems to assess their capabilities across geographies.

# Key Finding 5: Over 30% of SACs do not have a designated adherence lead

- We know that up to [70%](#) of patients are not adherent to their asthma therapies as prescribed with a resultant impact on both morbidity and mortality. A finding of interest from this work was that despite being specialised centres for asthma, 30% of SACs do not have an adherence lead to ensure this important behaviour is identified and modified.
- The majority of SACs nominated Pharmacists as the adherence leads, although Nurses and Doctors also featured in some centres as the adherence leads.
- It is [recommended](#) that every SAC should have a designated adherence lead responsible for medicines optimisation and to improve and maintain adherence.



## Why is this important?

- [Adherence checks are a requirement](#) for any patient being considered for Asthma Biologics. Individuals should be supported to improve their adherence for a minimum of 6 months before a biologic agent is considered severe asthma specialist centres should use an 80% adherence as the minimum acceptable level for commencing biologics.
- Given the criticality of this step in the approval pathway it may be advisable to assess for some sites whether capacity and throughput may be improved through designation of a formal adherence lead.

# Key Finding 6: Variation in staffing levels at SACs can impact MDT and service capacity impacting access to care

- Staffing levels for pharmacists, specialist nurses, administrative staff and consultants across SACs are variable and are based on the provision put in place by host Trusts, commissioned as SACs. Access to these specialists is of course a key determinant of a services capacity, with resource impacting a centre's ability to review and work up new patients, as well as to review and initiate patients on biologics at MDTs. MDTs are critical component of the severe asthma pathway and the asthma biologic approval process and [all potentially eligible patients must undergo an MDT review prior to initiation.](#)
- 13 of the 19 responding centres (68%) reported resource and capacity as the most significant service barrier in the context of improving services and access. This was described in various ways but a key theme being insufficient staffing, including medical staff, specialist nurses and pharmacist resource. In addition cases were reported where there was no dedicated funding for key members of MDTs.
- Respondents from 9 severe asthma centres reported a lack of access to psychology services, a key part of MDT provision, with postcode in some cases being a determinant of access.
- MDT capacity should be based on referral activity and demand, however this was also recognised by many SAC respondents as a potential bottleneck. To maintain or even reduce the time taken for eligible patients to be reviewed by an MDT, consideration will need to be given to current and future demand, particularly as a consequence of improved patient identification processes in a given system.

## Why is this important?

- Understanding of capacity and demand will be critical as improvements are made to identification earlier in the severe asthma pathway. As patient identification and referral improves, SACs and their networked sites may need to increase resource and capacity to improve throughput whilst maintaining the excellent quality of service and clinical oversight currently being delivered.

# Using the insight to support change

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- This exercise has shone light on the significant variation in severe asthma care offered across England.
- These differences stem from variations in pathways, configurations of services and resources available across the organisations and geographies.
- There is a risk that these variations may be leading to healthcare inequalities in severe asthma care.
- The service barriers most likely impeding access to severe asthma care and biologics were predominately related to resource and capacity however also included identification, prioritisation and access to diagnostics.
- An array of good practice and case studies were shared through this exercise with many excellent improvement initiatives presented.
- Regional data at AHSN level has been made available to local AHSN leads to support local quality improvement activity and looking at local variations in provision of care.

As part of the AAC Asthma Biologics programme, a number of resources are being developed to address the issues and barriers flagged through this exercise.



## Development of a Consensus pathway for Severe Asthma

A [recommended pathway](#) based on consensus timelines for patient journey and clear roles and responsibilities for primary, secondary and tertiary care

## Healthcare Professional Education

A suite of [educational resources](#) for primary and secondary care



## Patient Identification Tool

SPECTRA- a [clinical audit tool](#) to support the identification of potential and suspected severe asthma patients

## Tools to support Homecare and Home Monitoring

[Dashboards](#) to support services track homecare utilisation for biologic patients and an app for home monitoring



## AAC Asthma Biologics Toolkit

A [collection of quality improvement resources](#) to support improvement activity in Severe Asthma care

# Conclusions

- There is significant variation in pathways, services and practices around Severe Asthma Care in England.
- There are huge opportunities to bring specialist skills, knowledge, experience into primary care to support identification and management of potential severe asthma patients.
- Barriers to improving services across the pathway were identified in a number of areas which included: patient identification; diagnosis, pathway efficacy, resource and capacity.
- The AAC Asthma Biologics programme will be developing a suite of materials, resources and tools to assist at the different stages of the pathway.
- AHSN and system leaders are encouraged to review regional and local returns for this activity with a mind to developing tailored improvement plans.

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# National Benchmarking Exercise

*Appendices*

# Appendix 1: SAC good practice examples



## Good Practice

SAC respondents were asked to share any examples of good practice in their services.

### Responses

- 17 out of 19 respondents fed-back examples of good practice and innovation that they are delivering in their centres or across their networks.
- The examples included proactive identification, pathway improvements and introduction of new roles.

Challenge	Good practice shared by Severe Asthma Centres
<b>Identification</b>	<ul style="list-style-type: none"><li>• Methods being used to proactively identify patients who may have uncontrolled asthma include, screening A&amp;E patients that present with an asthma exacerbation, whilst they are an inpatient, when they are discharged and in primary care respiratory diagnostic hubs.</li><li>• To support proactive identification in ethnic minority groups, tackling health inequalities, multilingual resources have been produced explaining severe asthma and its management.</li><li>• Pathway improvements have been made to enable assessment to occur in a variety of different settings and by different professionals. This includes nurses running virtual clinics, specialist MDTs established in acute Trusts, clinicians running shortness of breath clinics and paediatric specialists running transition clinics for children transferring to adult services.</li><li>• To improve assessment of adherence and reduce delays to initiation, robust pharmacist-led processes have been established across clinical settings. New roles such as a severe asthma pharmacy technician roles have been embedded within organisations to support the assessment process.</li></ul>
<b>Resource</b>	<ul style="list-style-type: none"><li>• New roles have been established and embedded by Trusts to support assessment, prescribing, homecare and patient follow up. This includes Acute Trust based severe asthma nurses, severe asthma pharmacy technicians and pharmacist prescribers.</li><li>• To raise the priority of severe asthma at an organisational level, dashboards for severe asthma have been produced and are being used to measure outcomes. Prioritisation at individual patient level includes direct access for clinicians that require rapid advice to the severe asthma centre specialist teams using dedicated mobile phone numbers or a generic email inbox.</li></ul>
<b>Capacity</b>	<ul style="list-style-type: none"><li>• To improve the efficiency of pathways, severe asthma network sites have been established that enable collaboration. Efficiencies have been made through standardisation of processes for biologic initiation, homecare assessment and oral corticosteroid withdrawal.</li><li>• To increase capacity, patients are assessed and transferred to homecare on initiation or at their 2<sup>nd</sup> or 3<sup>rd</sup> appointment. Patients are supported with an education programme to allow for this early transfer.</li></ul>



# Appendix 2: Acute Trusts good practice examples



## Good Practice

Acute trust respondents were asked to share any examples of good practice in their services.

### Responses

- 48 respondents fed-back examples of good practice and innovation.

Challenge	Good practice shared by Acute Trusts
<b>Identification</b>	<ul style="list-style-type: none"><li>• Initiatives have been introduced to improve diagnostics and assessment including, introduction of nurse-led respiratory assessment units, unified assessment processes and weekly MDT meetings.</li><li>• To support proactive identification population health management approach's are being used to prioritise and review patients . This involves creating and running electronic system searches for primary care based that identifies patients who have had a recent asthma exacerbation and data bases Power BI, an analytics tool, to identify patients who may potentially be appropriate for a biologic.</li><li>• Some areas have increased the use of FeNO testing and introduced smart inhalers as part of assessment.</li></ul>
<b>Resource</b>	<ul style="list-style-type: none"><li>• New roles have been created to support asthma care: including clinicians with a specialist interest in asthma embedded into Acute Trusts and ward pharmacists trained to identify high risk patients.</li><li>• In some areas locally commissioned services and primary care initiatives are used to prioritise diagnosis, prescribing, and appropriate referral of patients with uncontrolled asthma.</li></ul>
<b>Capacity</b>	<ul style="list-style-type: none"><li>• Pathway initiatives have been implemented to make assessment and treatment more accessible. This has included consultant-led difficult asthma clinics, nurse-led biologic clinics , multi-professional airways clinics. A single point of contact for patients has also been established to navigate the pathway.</li><li>• A number of methods have been used to improve integrated working including establishment of adult integrated respiratory teams, regional networks for adults and paediatrics, integrated community asthma clinics, regular MDT meetings and intermediary nurse roles that link all parts of the pathway.</li><li>• Acute Trusts are supporting to preserve limited severe asthma centre capacity by administering injections in medical day wards. In addition, acute Trust staff are trained to carry out more advanced clinical management through competency-based opportunities provided by SACs including work shadowing.</li><li>• Homecare companies have been commissioned to provide services that enable home initiation, follow-up and monitoring of a biologic in new and established patients.</li><li>• Remote monitoring has been introduced by some Trusts to support patients for whom travelling to hospital on a regular basis would be difficult.</li></ul>

# Appendix 3: Primary care good practice examples



## Good Practice

Respondents were asked to share any examples of good practice in their services.

### Responses

- 23 respondents fed-back examples of good practice and innovation.

## Challenge Good practice shared by Primary Care practitioners

<b>Identification</b>	<ul style="list-style-type: none"><li>• Primary care clinicians are being upskilled on severe asthma management and FeNO testing. This is through educational programmes that are being delivered by GP respiratory leads and asthma nurses. Various audits have been conducted to support training and education.</li></ul>
<b>Resource</b>	<ul style="list-style-type: none"><li>• Prioritisation of resource is achieved in some PCNs through dedicated leadership and governance structures. This is through the establishment of dedicated system level respiratory leads and Asthma Death Prevention groups. Individual GP Practices have also introduced designated respiratory lead roles.</li><li>• Various resources have been developed or provided via Ardens templates to support patients initiate and manage their condition. This includes video links demonstrating inhaler technique and how to use in-check device. These resources and asthma plans are in some cases sent to patients via AccuRx. Some Practices use the Asthma Right Care scales to demonstrate the risk of SABA overuse. Self management plans are also co-produced with patients to improve adherence and understanding of asthma.</li><li>• Multiple respondents reported the use of digital tools to assist identification either through centrally developed clinical audit tools, through to the exploratory use of machine learning to identify patients through code cleansing.</li></ul>
<b>Capacity</b>	<ul style="list-style-type: none"><li>• Integrated pathways have been introduced to support review of complex respiratory patients. It includes direct access to diagnostics and regular MDT meetings. Additional funding in primary care has been allocated to support this. Severe Asthma Registers have also been developed at PCN level to coordinate management.</li><li>• GP Practices have improved access to diagnostics by establishing PCN level respiratory hubs and clinics that can carry out FeNO testing and spirometry. Some GP Practices reported planning for dedicated asthma diagnosis teams. Improvements have also been made to assessment processes by creating digital review forms that are completed by patients and reviewed by a clinician. Nurse-led remote reviews have also been introduced. These are supported by healthcare professionals who are trained to complete baseline observations in community-based patients.</li><li>• Pathways have been developed with local acute Trusts to review patients who have presented to A&amp;E with an asthma exacerbation on discharge. The review is carried out by a specialist asthma nurse and information of the review is shared back with the GP Practice.</li></ul>

# Appendix 4: Commissioning good practice examples

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## Good Practice

Respondents were asked to share any examples of good practice in their services.

### Responses

- 27 respondents fed-back examples of good practice and innovation.

Challenge	Good practice shared by primary care commissioning respondents
<b>Identification</b>	<ul style="list-style-type: none"><li>• Databases and system searches have been created to identify patients that may have uncontrolled asthma and need to be reviewed. To ensure there is capacity to review patients identified, community asthma nurses have been employed and Interface Clinical Services providing pharmacist support have been used.</li><li>• Various governance and leadership structures have been formed to elevate asthma as an organisational, and system priority. This includes respiratory transformation programme boards that focus on detection, managing and living with asthma. To support delivery, wrap-around community based services have been established. Dashboards have also been created that are shared across clinical settings that track trends in asthma related admissions cross-referenced with QOF data for asthma.</li></ul>
<b>Resource</b>	<ul style="list-style-type: none"><li>• There have been various initiatives to increase diagnostic capacity in primary care. This includes piloting community diagnostic hubs, spirometry services delivered at PCN level, community access to lung function testing and instating FeNO testing across all Practices within a specific area.</li><li>• Some areas have commissioned specific primary care respiratory services and introduced local incentive schemes. In addition, asthma best care indicators have been included in quality contracts.</li><li>• To increase capacity across clinical settings integrated respiratory teams have been created that are able to review patients with uncontrolled asthma and carry out assessments necessary for potential initiation of a biologic. Other methods used to integrate services include, virtual multidisciplinary multiorganisational team meetings, system-level asthma pathways, severe asthma guidelines, and specialist link workers from community respiratory team embedded into Primary Care Networks.</li><li>• Training resources have been developed focusing on standardisation of inhaler technique. Enhanced roles such as specialist nurse practitioners for respiratory are upskilling other health care professionals to be able to support complex case management.</li></ul>
<b>Capacity</b>	<ul style="list-style-type: none"><li>• Additional respiratory consultant resource has been embedded into pathways to ensure that assessment and referral of appropriate patients is as efficient as possible. Asthma pathways with allocated resource have also been developed specifically to manage care for children.</li></ul>