All Party Parliamentary Group for Respiratory Health

APPG Report

Improving Asthma Outcomes In The UK

November 2020

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All-Party Parliamentary Group for Respiratory Health

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Foreword

Jim Shannon MP

Chair, All-Party Parliamentary Group for Respiratory Health

The APPG is delighted to launch this report, following our intensive inquiry into the challenges around improving asthma outcomes and the impact it has on the lives of sufferers and their families.

The APPG was brought together to raise awareness of the importance of respiratory health and to promote effective policy for improving treatments and outcomes for respiratory illnesses.

The inquiry has given us real insights into the outstanding work carried out by so many professionals involved in asthma and the everyday impact the illness has on the sufferers themselves.

The impact of asthma is largely ignored by the media and the public and we are delighted that those who responded so generously to our call for evidence were able to offer crucial insights and opinion into the causes, treatment and management of asthma.

We hope that the outcomes of the report will assist the Department of Health and Social Care, the government and clinicians to look forward and implement the policy changes that will improve the lives of sufferers the most. We hope the report will also result in greater awareness and understanding of asthma.

We would particularly like to thank Professor Andrew Menzies-Gow, the National Clinical Director for Respiratory Health and Monica Fletcher, OBE, for their outstanding assistance in helping us to conduct the inquiry and produce the report.

Executive Summary

Asthma is a common long-term inflammatory condition that can affect people of all ages. Asthma attacks in the UK have increased by a third over the last decade[1] and the number of people affected by asthma in the UK is amongst the highest in the world, with up to 5.4 million people estimated to suffer from asthma.[2]

It also has an impact on patients' lives and the lives of their families. For many patients, the fluctuating nature of asthma results in infrequent symptoms, often relieved by the use of reliever inhalers and/or oral steroids. As these 'reliever' medications alleviate the symptoms, patients often ignore the use of background preventer medications.

Asthma is an inflammatory condition, and whilst reliever inhalers may manage episodic breathlessness, they do not manage the underlying inflammation – and if this persists, future breathless asthma attacks can occur. Severe attacks can lead to hospital admissions and even deaths.

Frequent breathless attacks can cause permanent, irreversible lung damage; therefore, we should have zero tolerance to asthma attacks, we should more closely measure and control the use of reliever medications, and set anti-inflammatory medication treatment as the standard of care.

Although not all patients will experience all of the symptoms, the most common symptoms of asthma include:

- Coughing
- Wheezing
- Shortness of breath
- Tightness in the chest

There are various reasons for breathlessness and these can vary in both children and adults. It can be difficult to tell the difference between asthma and other conditions that cause similar symptoms, such as other respiratory conditions, including pneumonia.

Asthma is a variable disease and the absence of consistent diagnostic criteria means that it is not possible to make unequivocal evidence-based recommendations on how to make a diagnosis of asthma.[3]

The British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) guidelines identify five key risk factors:

- previous near-fatal asthma
- previous admission for asthma, especially if in the last year
- requiring three or more classes of asthma medication
- heavy use of Short Acting Beta-2 Agonists (SABAs)
- repeated attendances at A&E for asthma care, especially if in the last year

Three of the most important risk factors are previous attacks, excess reliever medication and insufficient or incorrect use of preventer medication.

While we believe that best practice is a matter for the guideline bodies, we were impressed by the Asthma UK and British Lung Foundation Partnership (Asthma UK/BLF) patient-centric best practice which includes three key elements for every asthma patient:

- At least one annual review
- Inhaler technique check
- Written asthma action plan

[1] Asthma UK, *Asthma Death Toll in England and Wales is the Highest this Decade,* (August 2019) https://www.asthma.org.uk/about/media/news/press-release-asthma-death-toll-in-england-and-wales-is-the-highest-this-decade/#:~:text=New%20data%20shows%20asthma%20deaths,issues%20with%20basic%20asthma%20care [Last accessed 16th November 2020]

[2] Department of Health and Social Care, *Respiratory Disease: Applying All Our Health* (April 2015)

[3] BTS/SIGN. *SIGN 158 British Guideline on the Management of Asthma: Quick Reference Guide* (Last updated: July 2019) Pg. 2. https://www.brit-thoracic.org.uk/quality-improvement/guidelines/asthma/ [Last accessed 13th November 2020]

There was widespread support for these elements from our respondents and it remains an unfulfilled recommendation in the National Institute for Health & Care Excellence (NICE) Asthma guideline[4] and as an outstanding recommendation from the National Review of Asthma Deaths report (NRAD).[5]

We also note the potential of the BTS "care bundle", which consists of five elements and is a straightforward set of evidence-based clinical interventions or actions, which when performed reliably, can improve patient outcomes.[6] Although it is not formally recognised outside of BTS, it provides an opportunity for NICE to consider if it can be incorporated into their Quality Standards and whether it can be incentivised through the Quality and Outcomes Framework (QOF).

- **We recommend that the guideline discussions being undertaken by NICE, BTS and SIGN should consider these three elements of patient-centric best practice and the BTS care bundle with a view to incorporating the critical elements into routine clinical practice**

We heard convincing and unanimous evidence on the dangers of the over-reliance of reliever inhalers, known as SABAs, the frequent use of which and repeated requests for repeat prescriptions should trigger a clinical review.

We also heard of the dangers in the overuse of systemic oral corticosteroids (OCS) in asthma. OCS have long-term ill effects on the body (even from low doses) and side effects of OCS include diabetes, hypertension, cataracts, osteoporosis, glaucoma and obesity together with emotional impact. Their use should be minimised and the need for prescriptions beyond a predefined and consistent threshold should trigger a referral to a specialist asthma service.[7]

We believe that QOF is an appropriate mechanism to incentivise primary care and help prevent the overuse of reliever inhalers and OCS. QOF should include clearly defined thresholds of reliever inhaler prescribing designed to trigger follow-up action and improve adherence to preventative inhaler medication and to ensure that asthma patients are reviewed within two days of receiving emergency care, by appropriately trained individuals.

- **We recommend that when clinically agreed thresholds have been reached on repeat prescriptions and on the use of relief inhalers and courses of OCS, health records should be used as an automatic trigger for reviews, follow up appointments and referrals**
- **We recommend that QOF should be used to incentivise high quality outcomes for asthma, both in terms of improved quality of life as well as reduced asthma attacks, admissions and deaths**

We heard from a number of experts about the role of electronic records to allow greater communications between primary and secondary care and the use of digital technologies.

We were convinced by the evidence presented by the Health Data Research Hub for Respiratory Health (BREATHE) on the need for expanded use of available data sets within the NHS and believe that these could be used more widely and to better effect.

[4] NICE. *Asthma: Diagnosis, Monitoring and Chronic Asthma Management: NICE Guideline [NG80]*, Recommendations. (Published 29th November 2017, Last updated: 12 February 2020) https://www.nice.org.uk/guidance/ng80/chapter/Recommendations [Last accessed 13th November 2020]

[5] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths* [confidential enquiry report] (May 2014) Pg. xi-xii

[6] British Thoracic Society & Asthma UK, *Improving Outcomes in Asthma: Asthma Care Bundle* (22nd April 2016) https://www.brit-thoracic.org.uk/media/70102/bts-asthma-care-bundle-april-2016-v3.pdf [Last accessed 13th November 2020]

[7] NHS England. NHS Service Specifications. *Specialised Respiratory Services (adult) – Severe Asthma Specification (170002/S)* (2017) https://www.england.nhs.uk/wp-content/uploads/2017/04/specialised-respiratory-services-adult-severe-asthma.pdf [Last accessed 16th November 2020]

There is huge potential for NHS data to be shared and used more efficiently and to ensure information is more widely available. There is a strong argument that data interpretation could be transferred into clinical practice, such as identifying variations in care, prescribing and to monitor any changes that are implemented.

- **We recommend that the Government looks more fully into the possibilities of NHS data being made more widely available and allowing them to be interpreted by clinicians to improve asthma outcomes in clinical practice**

We commend the commitment of the NHS towards a digital future and the work of NHSX and NHS Digital to date but we believe that the NHS could still develop innovative technologies further. This includes better use of remote consultations, making it easy for people with asthma to attend appointments and self-manage effectively.

- **We recommend that the Government adopts a consistent and practical electronic health record for asthma, which can be shared across primary and secondary care, including urgent care. We also recommend that the NHS undertakes a specific assessment of innovative technologies that may be of most help to asthma patients**

We also heard consistent evidence that many patients are unable to master or unable to maintain good inhaler technique. We believe that an education campaign by the appropriate government body to highlight correct inhaler use will go some way to correcting this.

- **We recommend that the clinical bodies responsible for the upcoming revised guidelines take into account the need for greater awareness for patients on the correct use of inhalers and that the government and its executive agencies, NHSE and PHE/National Institute for Health Protection, run an information campaign designed to remind patients on the appropriate use of inhalers - relievers for uncontrolled symptoms and where prescribed, preventer inhalers**

A central theme in the evidence was the existence of multiple clinical guidelines, both national and local. This leads inevitably to inconsistencies in approach and practice throughout the country to the detriment of patients and their families. More guideline consistency and certainty, together with implementation is needed to improve care and increase the confidence patients have that they are being cared for in an integrated service.

The government must take the lead on this to make it happen.

- **We recommend that the government drives and monitors greater uniformity and consistency in the asthma guidelines and that they undertake a 12 monthly review of the new revised guidelines which are expected from the NICE/BTS/SIGN discussions in 2021**

We heard that the use of effective data for asthma could be improved. We discovered that the data currently available on severe asthma patients was insufficient to centrally collate figures on the total number of severe asthma patients. It was clear from the evidence we received that we don't know the exact number of severe asthma patients, nor the number that are being treated within the NHS, or the length of the waiting list.

"Asthma has traditionally not been seen as a priority at a national level"

In the recent Asthma UK Pilot Study[8], the impact on quality of life was notable:

- 68% said severe asthma holds them back in work and school
- 71% said severe asthma affects their social life
- 54% said it holds them back from going on holiday
- 66% said severe asthma has made them (or their child) anxious
- 55% said having severe asthma has made them (or their child) depressed

We find this unacceptable and agree with the many respondents who called for systems to more readily identify patients with severe asthma. An appropriate clinical code for severe asthma was suggested by a number of our respondents and this seemed to us to be an appropriate outcome.

- **We recommend that an appropriate clinical code needs to be created for severe asthma, to give certainty to patients and clinicians**

We were surprised at the lack of roll out of diagnostic hubs. The NICE Quality Standard recommends 'those responsible for planning diagnostic service support to primary care should consider establishing asthma diagnostic hubs to achieve economies of scale and improve the practicality of implementing the recommendations'. This recommendation was made two years ago and there has been little to no roll out of hubs since.

- **We recommend that the Government puts in place the necessary steps for the creation and roll out of diagnostic hubs for respiratory illnesses, including asthma, throughout primary care**

The use of biologics to treat severe asthma was widely recommended by both clinicians and severe asthma patients. Many clinicians viewed them as a better alternative to traditional OCS treatment for severe asthma. Patients stressed the importance of biologics in their treatment, and called for greater research into and awareness of biologics. We heard of the cost of biologic treatments and how this may be a factor in their low use. However, we support clinicians being able to make the choice to prescribe biologics in the best interests of their patients.

- **We recommend that clinicians be supported in their choice to prescribe biologics to severe asthma patients with adequate funding to support biologics services and wider education on the benefits of this form of treatment**

"Asthma care is not high priority in the UK"

"A public perception is that asthma is not a serious condition"

[8] "75% of people with severe asthma need regular emergency care, new Asthma UK survey finds". Asthma UK Pilot Study: https://www.asthma.org.uk/about/media/news/75-of-people-with-severe-asthma-need-regular-emergency-care-new-asthma-uk-survey-finds/ Last accessed, November 2020

Introduction

The APPG was concerned to hear that at the end of 2019, the latest figures on asthma showed that Asthma attacks in the UK had increased by a third over the last decade[9] and that the number of people affected by asthma in the UK is amongst the highest in the world.[10]

We decided that we would conduct an inquiry to investigate this further and to try to understand why this was the case, especially at this time when our health service is under enormous pressure due to the present COVID-19 pandemic and the anticipated winter pressures. It is important to help asthma sufferers stay well, be confident in the self-administration of their medication and stay out of hospital.

The report summarises the results of the All-Party Parliamentary Group for Respiratory Health (APPG) inquiry into asthma outcomes in the UK. It represents a six month inquiry into why improvements in asthma outcomes are stagnating in the UK and to recommend policy solutions for the NHS for implementation, to reverse the upward trend in asthma mortality.

We have tried to place the asthma debate both in policy and clinical terms and hope that our recommendations will improve the lives and treatment of asthma patients.

We invited internationally recognised experts in fields related to asthma to send written submissions. These experts ranged from clinical experts in primary, secondary and tertiary care to patient advocacy groups, national asthma champions and patients.

We received written submissions from over 30 individuals and organisations which included evidence from across the numerous asthma disciplines and we were very encouraged that there was such a high level of interest. This impressive response indicates an interest and passion for improvements in asthma, which strengthens the report.

To take this further and to consider this in a fuller context, we looked at common practices across a selection of European countries, with particular emphasis on Finland and the remarkable transformation in asthma care and outcomes in that country. We considered whether the changes in Finland were appropriate for the UK and whether it was adaptable and scalable in a different and larger UK demographic. The Finnish example demonstrated a systematic joined up approach, driven by the Government, which had considerable impact on asthma outcomes.[11]

We also looked at the UK in the wider context of other European countries. Due to the differences in clinical practice, data capture and the compiling of statistics the comparisons with Europe were not straightforward or easily made.

We were surprised by the number of different definitions of asthma. Although most were similar in most respects, our concern with different definitions is the possibility of varying consequences for diagnosis and treatment. While we note the differences and variations and we have our own views on this, it is ultimately not for us to determine a pre-eminent definition of asthma.

We also looked carefully into clinical practice and the care, treatment and management of asthma and severe asthma and we found both a partial consensus but also considerable differences of opinion among the clinical experts on how to improve asthma outcomes. We looked at the difference in understanding, treatment and management of severe asthma and how that is managed.

[9] Asthma UK, *Asthma Death Toll in England and Wales is the Highest this Decade,* (August 2019)

[10] Department of Health and Social Care, *Respiratory Disease: Applying All Our Health* (April 2015)

[11] T K Burki, *Asthma Control: Learning from Finland's Success,* The Lancet, Volume 7, Issue 3, Pg. 207-208 (March 2019) DOI: https://doi.org/10.1016/S2213-2600(19)30030-X [Last accessed 16th November 2020]

We received concerning testimony from a number of stakeholders that the common public and non-specialised Health Care Professionals' (HCPs) perception that asthma is not a serious condition has resulted in the dismissal of asthma as "it is just asthma". With the treatments available today and their proper and optimised use, we heard that we should have zero tolerance to asthma attacks and we are greatly sympathetic to this view.

We were concerned about the impact this had on patients' lives and a number of patients told us of the uncertainty, stress and concern caused to their lives as a consequence of the low level awareness of the seriousness of asthma.

We received multiple submissions that called for better awareness and understanding of asthma and severe asthma among the public, healthcare professionals, government, parliamentarians, patients and their carers.

Perhaps the most compelling evidence we received was around the treatment options. The biggest concern raised by our respondents was the over-reliance of reliever medication and we received compelling testimony that this was one of the single most important causes of unnecessary asthma deaths.

We also heard that newer treatments for severe asthma, such as biologics, were not well communicated by clinicians to patients and greater awareness of treatment options, especially by patients themselves would be helpful.

We noted widespread variation in referrals to specialist centres for severe or difficult to control asthma and the treatment of patients in referred care and we believe that greater consistency, awareness and timely treatment options would greatly benefit those patients for whom the referrals are necessary.

We agree with the necessity of a nationally co-ordinated approach to asthma care which should implement evidence based recommendations across primary and secondary care. All attacks need to be subject to an event analysis with input by specialists.

In expanding the availability of our findings, we hope to supplement the efforts of the many organisations, both clinical and non-clinical, which work tirelessly on behalf of clinicians, patients and their families to reduce the human, clinical and economic toll exerted by asthma each year and which affects so many lives.

There is far more opinion and value contained in the submissions than we can possibly represent in a report of this nature but the purpose of the inquiry was to allow different views and opinions to be expressed in order to assist us in our understanding of what needs to be done to improve asthma outcomes.

It is entirely a matter for the government, the Department of Health and Social Care (DHSC) and its Executive Agencies to make the policy decisions that will implement those improvements but we hope that we can offer some insights from clinical experts and other essential stakeholders in how this might be done. We will be looking to take the recommendations of this report forward and to engage meaningfully with Ministers and others.

We would like to thank everyone who has taken the time to respond to us - we were impressed by the dedication and commitment of so many organisations and individuals working to improve asthma outcomes and we commend their ongoing work. Some have been very generous with their time and it is thanks to them that we were able to produce this report.

In conclusion, we found convincing evidence that there is an opportunity to reduce the unnecessary variation in asthma outcomes currently seen in the UK, improve the lives of patients with asthma throughout the UK, and reduce the unnecessary burden on our healthcare system and society caused by poorly controlled asthma.

We repeatedly heard the message that there is a need for all patients to receive basic asthma care when needed, for improved patient monitoring and for common and clear referral criteria for hard-pressed primary care clinicians and other HCPs.

There is a need for asthma guidelines to be consolidated and more assistance given to patients with poor or over reliance on reliever inhalers and there needs to be a more streamlined system between primary and secondary care.

What Is Asthma?

Asthma is generally regarded as a chronic inflammatory condition of the airways. However, when we attempted to include a definition of asthma and severe asthma we discovered that there are widespread definitional differences among organisations and the fact that there is no one, single definition of asthma or severe asthma. Most guideline or regulatory bodies used their own preferred definition and while there were similarities to them all, this caused us some concern.

Our concern was twofold; first, we could not be sure of consistency in definition for our comparison with other European bodies and countries and, secondly, we could not be sure if the different definitions led to varying clinical treatment options and outcomes and if the diagnosis for or against asthma was consequently comparable or consistent.

There are however, some common symptoms of asthma, which are accepted across the healthcare system, such as:

- Coughing
- Wheezing
- Shortness of breath
- Tightness in the chest

The reasons for breathlessness can vary in both children and adults, especially older adults, and it can be more difficult to tell the difference between asthma and other conditions that cause similar symptoms, such as heart disease or pneumonia. Allergy UK, in their evidence, stated that some asthma exacerbations in children can be triggered by an allergic reaction.[12]

The UK and Global guideline bodies all state that proof of symptoms alone should not be enough to diagnose asthma, [13, 14, 15] and recommend capturing a clinical history supported by objective measurements, such as lung function tests.[16]

"There is no one, single definition of asthma or severe asthma"

[12] Allergy UK's Evidence

[13] BTS/SIGN. *SIGN 158 British Guideline on the Management of Asthma: Quick Reference Guide* (Last updated: July 2019) Pg. 2

[14] NICE. *Asthma: Diagnosis, Monitoring and Chronic Asthma Management: NICE Guideline [NG80],* Recommendations. (Last updated: 12 February 2020)

[15] GINA. 2020 *GINA Report, Global Strategy for Asthma Management and Prevention,* Chapter 1: Definition Description and Diagnosis of Asthma (2020) Pg. 20. https://ginasthma.org/wp-content/uploads/2020/06/GINA-2020-report_20_06_04-1-wms.pdf [Last accessed 20th October 2020]

[16] NICE. *Asthma: Diagnosis, Monitoring and Chronic Asthma Management: NICE Guideline [NG80],* Recommendations. (Last updated: 12 February 2020)

International Comparisons

We looked at the comparisons with other European countries in regards to asthma admission rates and mortality and while the evidence we received was varied and diverse, there was general agreement from the respondents that there were challenges on the data sources, for example in the lack of data sharing and data coding, that led to many of them urging caution in making any meaningful European comparisons.

The Royal College of Physicians' (RCP) National Asthma and Chronic Obstructive Pulmonary Disease (COPD) Audit Programme told us that the UK does not share data across Europe in a systematic way[17] and does not collect comparable information that may help us understand why the variations exist.

They also commented that generally we don't understand the epidemiology of asthma deaths well enough due to the current standard of asthma diagnosis in the UK. In the UK the majority of asthma cases are diagnosed by symptoms, history, and response to treatment and infrequently, the use of objective tests. As a result, some patients diagnosed with asthma in the UK may not be asthmatic at all.

Asthma UK/BLF suggested that the problem lay in the different ways of coding asthma diagnosis, hospital admissions and deaths across countries, which makes these types of international comparisons difficult to make.[18] This was reinforced by the Association of Respiratory Nurse Specialists (ARNS) who stated that it "may be an assumption which is not necessarily correct. Differences in diagnostic processes, care provision and the generalist v specialist approach, as well as data collection and recording may all contribute to differences in incidence, prevalence, morbidity and mortality statistics."[19]

The Asthma UK Centre for Applied Research (AUKCAR) told us that comparing the UK as a whole to the rest of Europe may be unhelpful due to differences in health care delivery and reporting mechanisms and that it was more important to consider the considerable variation in care across the UK.

As a result, the perception we were left with was that while the comparison with other countries may not be possible, nonetheless the statistics (numbers of admissions and deaths) are alarming. Most respondents agreed that the fragmented approach to asthma care in the UK was the key issue in the UK and a major contributory factor to the UK being perceived to be lagging behind other European countries.

We are happy to accept the unanimous advice of our expert stakeholders on this point and our inquiry focuses on the situation within the UK.

"Comparing the UK as a whole to the rest of Europe may be unhelpful"

[17] Royal College of Physicians, *National Asthma and COPD Audit Programme (NACAP)* https://www.rcplondon.ac.uk/projects/national-asthma-and-copd-audit-programme-nacap[Last accessed 16th November 2020]

[18] Asthma UK/BLF's Evidence

[19] Association of Respiratory Nurse Specialists' Evidence

The Role Of Government

Support for improvements in asthma from successive UK Governments has been characterised by including asthma in wider respiratory health policy rather than as stand-alone initiatives. Consequently, there is a limited focus on asthma itself and a reduced ability to understand and identify strategies that would improve asthma-specific outcomes. For many years, Governments have tended to rely on the outcomes and strategies from executive, regulatory and other bodies, such as NICE and from guideline groups and patient advocacy groups.

Ministers have repeatedly rejected calls for a national asthma strategy or a taskforce for asthma sufferers, preferring to point to a range of initiatives and guidelines developed with external stakeholders, including clinicians, professional organisations and third sector bodies.[20]

NICE Quality Standards cover both diagnosis and treatment and are designed to improve care quality and reduce the risk of attacks.[21] This guidance is referred to extensively in both the Outcomes Strategy and the Long Term Plan.

Government policy in relation to asthma is largely contained in the Outcomes Strategy for COPD and Asthma, published in 2011, followed by a NHS Companion Document in 2012, to set out 'best practice to achieve improved outcomes'[22] but we note that these have not been updated for some time.

Despite asthma being included in more general respiratory health policy, Ministers have described asthma care as a 'clinical priority',[23] and have repeatedly referenced the commitments contained in the Long Term Plan, which was published in 2019. This contains an 'ambition' to 'transform our outcomes [for those with respiratory disease] to 'equal, or better, our international counterparts'.[24]

"Improving care for people with lung disease is crucial to this Government. We do not need reams of new plans or strategies, but continued action to implement existing plans, including the NHS outcomes framework, which details NHS priority areas and includes reducing deaths from respiratory disease as a key indicator."

Steve Brine MP
Parliamentary Under Secretary of State for Health
House of Commons
14th November 2017

[20] Official Report WPQ number 107275 11th October 2019

[21] NICE. *Asthma: Diagnosis, Monitoring and Chronic Asthma Management: NICE Guideline [NG80],* Overview. (Published 29th November 2017, Last updated: 12 February 2020) https://www.nice.org.uk/guidance/ng80

[22] An Outcomes Strategy for COPD and Asthma 2011; *Long Term Plan Respiratory Disease An Outcomes Strategy for COPD and Asthma:* NHS Companion Document 2012

[23] Official Report, WPQ number 286317 9th September 2019

[24] Official Report, WPQ number 277730 26th July 2019; Long Term Plan Respiratory Disease para 3.82

We agree with the Minister and many of our respondents that the means to improve asthma outcomes already exist and believe that the proper implementation of existing guideline recommendations is central to this.

The NHS Long Term Plan sets out a number of proposals in relation to respiratory health, including an ambition to 'do more to detect and diagnose respiratory problems earlier'. According to the updated version of the plan, 'primary care networks will support the diagnosis of respiratory conditions',[25] while 'more staff in primary care will be trained and accredited to provide the specialist input required to interpret results'.[26]

We note however, that we still do not see diagnostic hubs being rolled out, very few specialist asthma nurses in primary, community or hospital care and limited access to respiratory specialists in secondary care in paediatrics and for adults.

In addition, no assessment has been made of the variation in asthma-related deaths across Clinical Commissioning Groups in England.[27]

The Plan also includes pharmacists in primary care networks, who will now 'undertake a range of medicine reviews, across all clinical conditions. However, the revised Service Specification (Sept 20) for Structured Medicine Reviews under the Primary Care Network Contract does not prioritise patients with asthma to be considered for such a review by appropriately trained individuals.

To reinforce this push at pharmacy level, the Community Pharmacy Contractual Framework – for 2019/20 to 2023/24 includes an obligation on pharmacies to "show evidence that asthma patients, for whom more than six short-acting bronchodilator inhalers were dispensed without any corticosteroid inhaler within a six month period, have since the last review point been referred to an appropriate health care professional for an asthma review".[28]

NHS England and NHS Improvement has been running a severe asthma collaborative project to improve patient experience, outcomes and safety through improved access to specialist multidisciplinary teams for assessment and review.

Under this project, all specialised providers are asked to develop a networked model of care as the vehicle for delivering an optimal pathway and maximising patient outcomes and experience.[29] Several of our respondents called for increased multi-disciplinary team (MDT) assessment of asthma patients in secondary and tertiary care and under the project, all patients newly diagnosed with severe asthma receive a review of their care by a specialist asthma MDT, hosted by one of the 14 designated severe asthma centres in England.

Despite prompting from a number of parliamentarians, Ministers remain adamant that there are no plans to increase the number of these centres.[30]

The DHSC maintains working relations with non-government bodies, including in the development of policy initiatives. These include charities such as Asthma UK/BLF, with which The National Health Service Cardiovascular Disease-Respiratory national programme was developed.[31]

[25] NHS England, *The NHS Long Term Plan,* Chapter 3: Further Progress on Care Quality and Outcomes (7 January 2019) Pg.66 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

[26] NHS England, *The NHS Long Term Plan* (7 January 2019) Pg.66

[27] Official Report, Written Questions, HL 5869, 17th June 2020

[28] PSNC, NHS England & NHS Improvement, Department of Health and Social Care. *The Community Pharmacy Contractual Framework for 2019/20 to 2023/24: Supporting Delivery for the NHS Long Term Plan.* Annex B – Summary of the Pharmacy Quality Scheme for 2019/20 (22 July 2019) Pg. 21 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/819601/cpcf-2019-to-2024.pdf

[29] Official Report WPQ number 277730 26th July 2019

[30] Official Report WPQ number 277731 26th July 2019

[31] Official Report WPQ number 281136 3rd September 2019

The department also works closely with professional bodies, such as the RCP, whose National Asthma and COPD Audit Programme – which aims to improve quality of care, services, and clinical outcomes for patients with asthma and COPD by collecting and providing data on a range of indicators.

An online survey in 2019 found that 61% of asthma sufferers interviewed think very little or nothing is being done by the Government to reduce avoidable asthma deaths in the UK.[32]

Almost all the respondents to our inquiry identified the existence of multiple asthma guidance initiatives as confusing and unnecessary.

The RCP told us that "National audit data collected from England, Scotland and Wales indicates that the standard of care against national guidelines (NICE and BTS) and recommendations from NRAD are variable and on the whole substandard. This applies to both primary care in Wales and in acute hospital care across the three nations".[33]

This is a stark admission by the leading professional body for physicians in the UK and this, in itself, should lead to improved application of unified national guidelines in 2021.

Our experts identified clear areas for improvement within the health system, including:

- ensuring all patients receive basic asthma care, by appropriately trained healthcare professionals
- clearer referral criteria for primary care clinicians
- improved patient monitoring and those over-relying on blue (preventer) inhalers must be identified followed by optimisation of care
- increased communication between primary and secondary care

We commend the government for the positive steps they are taking to improve asthma outcomes, although these tend to be in the wider context of respiratory disease. We welcome the potential of the outcomes from the Long Term Plan and the work being undertaken by NHS RightCare and Getting It Right First Time. However, there is little, if any, differentiation between asthma and severe asthma within the government's policies and initiatives.

"An online survey in 2019 found that 61% of asthma sufferers interviewed think very little or nothing is being done by the Government to reduce avoidable asthma deaths in the UK"

[32] ComRes online poll between 14th and 15th August 2019

[33] Royal College of Physicians' Evidence

Asthma In Figures

Asthma deaths in the UK have increased by a third over the last decade[34]	**The number of people affected by asthma in the UK is amongst the highest in the world with up to 5.4 million people in the UK estimated to suffer from asthma**[35]	Three people every day die in the UK from asthma[36], which remains amongst the highest in Europe[37, 38]
Hospital admission (2012)[39] **and mortality rates (2011)**[40] **of asthma in adults in the UK are amongst the highest across the 'Big Five' European countries**	22.5 million blue inhalers are dispensed to asthma patients each year (an average of 5 per diagnosed asthma patient; 3+ blue (reliever) canisters per year associated with a two-fold increased risk of severe asthma attack[41]	130,000 patients receive 3+ courses of oral corticosteroids per year[42]
Studies show that over two out of three asthma deaths are associated with major potentially preventable factors[43, 44] **and could be prevented with better routine care**[45]	Asthma exacerbations lead to over 77,000 hospital admissions each year[46]	**It is estimated that asthma leads to a direct cost to the NHS of £1 billion and an indirect cost to society, due to time off work and loss of productivity, of £1.2 billion**[47]

[34] Asthma UK, *Asthma Death Toll in England and Wales is the Highest this Decade,* (August 2019)

[35] Department of Health and Social Care, *Respiratory Disease: Applying All Our Health* (April 2015)

[36] Asthma UK. *Frequently Asked Questions* https://www.asthma.org.uk/advice/understanding-asthma/faqs/#goaway [Last accessed 16th October 2020]

[37] Department of Health. *An Outcomes Strategy for People with Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England.* London: DH, (2011) https://www.gov.uk/government/publications/an-outcomes-strategy-for-people-with-chronic-obstructive-pulmonary-disease-copd-and-asthma-in-england [Last accessed, 13th November 2020]

[38] Wolfe I, Cass H, Thompson MJ et al. *Improving Child Health Services in the UK: Insights from Europe and their Implications for the NHS reforms.* BMJ (2011);342:d1277. www.ncbi.nlm.nih.gov/pubmed/21385800 [Last accessed 13th November 2020]

[39] European Respiratory Society. *European Lung White Book.* Chapter 12: Adult Asthma (2019) https://www.erswhitebook.org/chapters/adult-asthma/ [Last accessed 13th November 2020]

[40] European Respiratory Society. *European Lung White Book.* Chapter 12: Adult Asthma (2019)

[41] Bloom, C.I., Cabrera, C., Arnetorp, S. et al. *Asthma-Related Health Outcomes Associated with Short-Acting β2-Agonist Inhaler Use: An Observational UK Study as Part of the SABINA Global Program.* Adv Ther 37, 4190–4208 (2020). https://doi.org/10.1007/s12325-020-01444-5 [Last accessed 16th November 2020]

[42] Asthma UK, *Living in Limbo: the Scale of Unmet Need in Difficult and Severe Asthma* (2019) Pg. 10.https://www.asthma.org.uk/69841483/globalassets/get-involved/external-affairs-campaigns/publications/living-in-limbo/living-in-limbo---the-scale-of-unmet-need-in-difficult-and-severe-asthma.pdf [Last accessed 13th November 2020]

[43] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report]* (May 2014) Pg. 4

[44] British Thoracic Association. *Death From Asthma in Two Regions of England* BMJ (Oct 30th 1982) 285(6350): 1251–1255 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1499823/

[45] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report]* (May 2014) Pg.43

[46] Asthma UK, *Asthma Facts and Statistics* (2017) https://www.asthma.org.uk/about/media/facts-and-statistics/ [Last accessed, 13th November 2020]

[47] Asthma UK: *Living on a Knife Edge* (2004)

Asthma In Figures

There is currently no recognised single test for asthma. Instead, it is often diagnosed through the signs and symptoms experienced by the patient[48]	Every 10 seconds someone has a potentially life-threatening asthma attack in the UK[49]	10% of patients died within 28 days of discharge[50]
64% of patients have no follow-up in primary care following hospitalisation[51]	82% difficult and severe asthma patients are not being referred to specialists[52]	3.24 million patients are still not receiving the most basic level of care[53]
22-63% – average adherence among patients to preventer medicines[54]	3 or more – blue (reliever) inhalers a year per patient is associated with increased visits to hospitals[55, 56]	**39% – proportion of patients who were prescribed excessive reliever medication in the year before their death caused by asthma**[57]

The NHS England Specialised Respiratory Services (adult) Severe Asthma service specification seeks to address this when it states: "There is a common misconception that severe asthma patients are an extreme example of the milder version of the disease...It is therefore essential to differentiate severe from milder versions of the disease and to consider it as a separate condition that requires specialist services to improve the health of this patient group, which continues to have a clear unmet need."[58]

[48] BTS/SIGN. *SIGN 158 British Guideline on the Management of Asthma: Quick Reference Guide* (Last updated: July 2019) Pg. 2

[49] Asthma UK, *Asthma Facts and Statistics* (2017)

[50] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report]* (May 2014) Pg. x

[51] Asthma UK, *The Reality of Asthma Care in the UK: Annual Asthma Survey 2018 Report.* (2019) Pg.4 https://www.asthma.org.uk/578f5bcf/globalassets/get-involved/external-affairs-campaigns/publications/annual-asthma-care-survey/annual-asthma-survey-2018/asthmauk-annual-asthma-survey-2018-v7.pdf [Last accessed 13th November 2020]

[52] Asthma UK, *Living in Limbo: the Scale of Unmet Need in Difficult and Severe Asthma* (2019) Pg.11

[53] Asthma UK, *The Reality of Asthma Care in the UK: Annual Asthma Survey 2018 Report.* (2019) Pg.7

[54] C B Bårnes and C S Ulrik, *Asthma and Adherence to Inhaled Corticosteroids: Current Status and Future Perspectives,* Respiratory Care (March 2015) 60 (3) 455-468; DOI: https://doi.org/10.4187/respcare.03200 [Last accessed 13th November 2020]

[55] Stanford RH, Shah MB, D'Souza AO et al. *Short-acting β-agonist Use and its Ability to Predict Future Asthma-related Outcomes.* Ann Allergy Asthma Immunol (October 2012)109(6):403–407. https://doi.org/10.1016/j.anai.2012.08.014 [Last accessed 13th November 2020]

[56] Bloom CI, Cabrera C, Arnetorp S, etc. *Asthma-Related Health Outcomes Associated with Short-Acting β2-Agonist Inhaler Use: An Observational UK Study as Part of the SABINA Global Program* (2020)

[57] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report],* (May 2014) Pg.57

[58] NHS England. NHS Service Specifications. *Specialised Respiratory Services (adult) – Severe Asthma Specification* (170002/S) (2017)

Asthma Management In The UK:
The Current Clinical Situation

Finland case study

The Finnish Asthma programme is generally seen as the gold standard within European asthma care, given its success in tackling Finland's asthma issues. The Programme itself was built on a joined-up multidisciplinary national campaign that included patients, professionals and government and extended officially over 10 years, however extensive planning and engagement meant that benefits were already apparent before the official launch.[59]

The programme's results were obvious immediately and continued to grow as it went on. The number of days of asthma-related hospital admissions in Finland more than halved over the course of the programme,[60] while asthma-related visits to Finnish emergency rooms also dropped by 46%.[61]

There was an increase in the percentage of patients diagnosed with asthma (6·5% in 1996 to 10·0% in 2006),[62] the programme led to savings[63] as patients were better controlled, which led to hospital admissions falling and patients taking fewer days off work.[64]

The programme was an unqualified success, and one that is still widely recognised today. When explaining this success, Tari Haahtela (Chair of Filha's asthma programme from 2002) stated:

"(We) made clear goals, defined tools to reach the goals, decided on outcomes to be measured (disease severity, hospitalisations and costs), and then implemented a long-term educational programme. The patients started to march out of emergency rooms and out of hospitals"[65]

Almost all our respondents outlined in some detail the main elements of asthma care, with general agreement on the basic condition of asthma services within the UK - that there are considerable challenges in the treatment and management of asthma. We heard of poor communication between all levels of care but especially between primary and secondary care,[66, 67] the effectiveness of asthma training for GPs and practice nurses[68, 69, 70] and multiple asthma guidelines within the UK.[71]

We note that there is widespread agreement that the impact of asthma on patients' lives was considerable and could be improved. This was due mainly to poor understanding around the appropriateness and timing of referrals to secondary and tertiary care, over-reliance of reliever and OCS medications and poor compliance with the standard asthma treatments.

Asthma is normally differentiated for diagnosis and treatment in three age groups:

- Children under the age of five
- Children and young people aged between five and 18
- Adult asthma

The latest NICE asthma guideline outlines the recommended diagnostic pathways for each age range and rather than detail these here, the guideline should be read in conjunction with this report.[72]

[59] Haahtela T, Tuomisto L, Pietinalho A, et al. *A 10 Year Asthma Programme in Finland: Major Change for the Better.* Thorax. 61(8), 663-670. (2006, Aug) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2104683/ [Last accessed 13th November 2020]

[60] T K Burki, *Asthma Control: Learning from Finland's Success,* The Lancet, Volume 7, Issue 3, Pg. 207-208 (March 2019) DOI: https://doi.org/10.1016/S2213-2600(19)30030-X [Last accessed 13th November 2020]

[61] T K Burki, *Asthma Control: Learning from Finland's Success,* The Lancet, Volume 7, Issue 3, Pg. 207-208 (March 2019)

[62] T K Burki, *Asthma Control: Learning from Finland's Success,* The Lancet, Volume 7, Issue 3, Pg. 207-208 (March 2019)

[63] Kauppi, P., Linna, M., Martikainen, et al. *Follow-up of the Finnish Asthma Programme 2000-2010: Reduction of Hospital Burden Needs Risk Group Rethinking.* Thorax, 68(3), 292-293. (2013). https://doi.org/10.1136/thoraxjnl-2011-201028 [Last accessed 16th November 2020]

[64] T K Burki, *Asthma Control: Learning from Finland's Success,* The Lancet, Volume 7, Issue 3, Pg. 207-208 (March 2019)

[65] T K Burki, *Asthma Control: Learning from Finland's Success,* The Lancet, Volume 7, Issue 3, Pg. 207-208 (March 2019)

[66] Dr Mark Levy's Evidence

[67] PCRS's Evidence

[68] Professor Andrew Bush's Evidence

[69] Allergy UK's Evidence

[70] Heather Matthews's Evidence

[71] Prof Dominic Shaw's Evidence

[72] NICE. *Asthma: Diagnosis, Monitoring and Chronic Asthma Management: NICE Guideline [NG80],* Overview.

Asthma Management In The UK:
Asthma Treatment

There are a wide range of commonly prescribed medications used to treat asthma. In the first instance in primary care, most patients will be prescribed inhalers to manage the causes and relieve the symptoms.

The most common and recognisable are the inhaled reliever inhalers and the inhaled low dose corticosteroid inhalers (known as preventer inhalers).

- **Quick-relief inhalers/SABA.** These are fast-acting inhaled bronchodilators and are classed as rescue inhalers. They are normally used as needed to dilate the airways and make breathing easier. Although these medications can help prevent an impending asthma attack, quick-relief inhalers do not tackle underlying inflammation, which may persist and result in further attacks
- **Preventer inhalers.** These are preventive, inhaled medications usually containing anti-inflammatory corticosteroids to help reduce inflammation and swelling in the airways that lead to asthma symptoms. They reduce or eliminate asthma flare-ups and achieve the best patient outcomes. (source for both Asthma UK/BLF). Their correct use should negate or reduce the need for rescue inhalers

If the inhalers are not controlling symptoms effectively, there are a number of additional treatments that can be prescribed. These include:

- **Long-acting bronchodilators (LABAs),** which help keep the airways open for longer up to 24 hours and relax the muscles around them. These are commonly prescribed in the same inhaler as the preventer inhaler
- **Leukotriene receptor antagonists (LTRAs).** These are an oral anti-inflammatory medication classed as an 'add on' treatment. They come in tablet form and are sometimes called preventer tablets. NICE guidelines recommend LTRAs for patients who are using their preventer inhaler correctly but still having symptoms
- **Slow-release theophylline, beta-2 agonist tablets, Long-acting muscarinic receptor antagonists (LAMAs).** Bronchodilators, in tablet, nebulised, or inhaler form, these act as an 'add on' treatment in addition to prescribed inhalers
- **Systemic corticosteroids** in tablet or liquid form (or sometimes injection) will be added, if add on therapies are ineffective and/or in the case of an emergency respiratory crisis. Under most guidelines, any patient prescribed steroids two or more times per year, or for long periods of time, are recommended to be referred to an asthma specialist for further review

  Systemic corticosteroids can be an essential option for patients with severe asthma but they can have significant side effects and the evidence we received suggested that patients should be on the lowest possible dose necessary to keep asthma symptoms controlled.

  Patients on regular systemic corticosteroids tablets, whose symptoms are still not under control, or if the symptoms can only be controlled by high-dose preventer inhalers or regular steroid tablet use, should be referred for assessment by a consultant at a specialist asthma clinic.

  These can be prescribed along with existing medication or in an adjusted combination of treatments.
- **Biologic therapies,** also known as monoclonal antibodies (mAbs) are a more recent treatment for people with certain types of severe asthma. However, we received evidence that a large majority of patients who are eligible still do not have access to them.[73]

  The treatment shortfall in the use of biologics is estimated at 80% by Asthma UK/BLF, who also told us that the current NHS asthma care pathway does not take account of the availability of these new treatments and so most people with severe asthma are still reliant on toxic oral corticosteroids in primary and secondary care.

  Therefore it is important that there is resource to support adequate numbers of asthma specialists for populations across the UK, who can initiate biologic therapies.

[73] Bloom CI, Walker S, Quint JK. *Inadequate Specialist Care Referrals for High-risk Asthma Patients in the UK: an Adult Population-based Cohort 2006-2017.* J Asthma. (2019 Oct 9) 1-7 https://pubmed.ncbi.nlm.nih.gov/31550948/ [Last accessed 16th November 2020]

Asthma Management In The UK:
Overuse Of Relief Inhalers

There were a number of serious concerns raised by most of our respondents on the treatment and management of asthma. These mainly centred around the over-reliance of reliever inhalers.

Several studies have shown that over-reliance by patients of the reliever inhalers may lead to reduced use of preventer inhalers and to a greater risk of preventable attacks.[74, 75] These conclusions were supported by our respondents, many of whom focused on the dangers of over-reliance on SABA medication.[76, 77, 78, 79]

All our respondents on this point emphasised the need for them to be seen as short term 'rescue medication'[80] as opposed to a long term solution to asthma symptoms. NRAD included evidence that regular over-use of short acting relievers increases the risk of asthma attacks[81, 82], hospitalisations and deaths.[83, 84]

The Global Initiative for Asthma (GINA) no longer recommends treating adolescents and adults with SABA alone for symptom relief,[85] while the SABINA (SABA use In Asthma) study found that high SABA inhaler use was frequent among UK patients and was associated with a significant increase in exacerbations and asthma-related healthcare reliance, regardless of treatment step or asthma severity and stated that there is a need to align SABA prescription practices with current treatment recommendations.[86]

The SABINA study defined high SABA use as ≥ 3 SABA canisters per year and that high use was observed in over one-third of UK asthma patients and those prescribed excess SABA had twice as many asthma attacks.[87]

A 2018 study commissioned by The Lancet,[88] recommended a change to prevention strategies, which included the recording of the number of reliever prescriptions to reduce the risk of an asthma attack. NICE considered including an assessment of reliever use and a record of the number of attacks in the 2020 changes to the GP QOF, but this did not happen.

All the respondents wanted to see reliever inhaler prescription limited. This ranged between respondents to between two a year, three a year[89], four in four months[90] and four a year. [91]

[74] O'Byrne P, Jenkins C and Bateman E. *The Paradoxes of Asthma Management: Time for a New Approach?* Eur Respir J. 2017;50:1701103. https://doi.org/10.1183/13993003.01103-2017; [Last accessed 16th November 2020]

[75] Partridge M, van der Molen T, Myrseth S-E and Busse W. *Attitudes and Actions of Asthma Patients on Regular Maintenance Therapy: the INSPIRE Study,* BMC Pul Med. 2006;6:13. https://doi.org/10.1186/1471-2466-6-13 [Last accessed 16th November 2020]

[76] Asthma UK Centre for Applied Research's Evidence

[77] Cheryl Seymour's Evidence

[78] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report]* (May 2014) Pg. 37

[79] Dr Adel H Mansur's Evidence

[80] Allergy UK's Evidence

[81] Global Initiative for Asthma. Global Strategy for Asthma Management and Prevention. 2020 Update. https://ginasthma.org/wp-content/uploads/2020/06/GINA-2020-report_20_06_04-1-wms.pdf

[82] Asthma UK: Reducing prescribing errors in asthma care. Available at: https://www.asthma.org.uk/support-us/campaigns/publications/nrad-one-year-on/

[83] Stanford RH, Shah MB, D'Souza AO, et al. Short-acting β-agonist use and its ability to predict future asthma-related outcomes. Annals of Allergy, Asthma & Immunology. 2012; 109: 403-407

[84] Nwaru BI, Ekström M, Hasvold P, *et al.* Overuse of short-acting β2-agonists in asthma is associated with increased risk of exacerbation and mortality: a nationwide cohort study of the global SABINA programme. *Eur Respir J.* 2020;55(4):1901872

[85] GINA. *Pocket Guide For Asthma Management and Prevention.* Update on GINA Recommendations For Mild Asthma (2020) Pg. 7. https://ginasthma.org/wp-content/uploads/2020/04/Main-pocket-guide_2020_04_03-final-wms.pdf [Last accessed 13th November 2020]

[86] Janson C, Menzies-Gow A, Nan C, et al. *SABINA: An Overview of Short-Acting β2-Agonist Use in Asthma in European Countries.* Adv Ther. (2020 Mar) 37(3):1124-1135. https://pubmed.ncbi.nlm.nih.gov/31981105/ [Last accessed 13th November 2020]

[87] Bloom, C.I., Cabrera, C., Arnetorp, S. et al. *Asthma-Related Health Outcomes Associated with Short-Acting β2-Agonist Inhaler Use: An Observational UK Study as Part of the SABINA Global Program* (2020)

[88] Pavord ID, Beasley R, Agusti A et al. *After Asthma: Redefining Airways Diseases.* Lancet. 2018;391:Pg 350–400. https://doi.org/10.1016/S0140-6736(17)30879-6 [Last accessed 16th November 2020]

[89] Dr Mark Levy's Evidence

[90] Cheryl Seymour's Evidence

[91] Dr Adel H Mansur's Evidence

They felt that patients who are using excessive numbers of inhalers should be flagged[92, 93] and identified[94, 95, 96] and immediately seen by an asthma trained clinician.[97] There was overwhelming support for changing the existing guidelines to address over-use of reliever prescribing but we note that there are currently no incentives for this and recent calls for this to be included by NICE within the current QOF was rejected.

There was also great concern expressed over low adherence to preventative inhalers.[98, 99] Various methods to address use of preventer medication were suggested, such as Great North Children's Hospital's (GNCH) idea of making asthma preventer medication prescriptions free on the NHS,[100] or Dr Mark Levy's suggestion that those using less than 75% of their prescribed preventer inhalers a year should be immediately flagged to be seen by an asthma trained clinician.[101]

We cannot ignore the significant and compelling evidence we received on the over-use of quick relief inhalers. Our respondents were consistent in their calls for better education for patients on inhaler technique and the introduction of use thresholds for referral.

We recommend that the clinical bodies responsible for the upcoming revised guidelines take into account the need for greater awareness for patients on the correct use of inhalers and that the government and its executive agencies, NHSE and PHE/National Institute for Health Protection, run an information campaign designed to remind patients on the appropriate use of inhalers – relievers for uncontrolled symptoms and, where prescribed, preventer inhalers.

"We cannot ignore the significant and compelling evidence we received on the over-use of quick relief inhalers."

[92] Dr Adel H Mansur's Evidence

[93] Great North Children's Hospital's Evidence

[94] Dr Mark Levy's Evidence

[95] Asthma UK Centre for Applied Research's Evidence

[96] Dr Adel H Mansur's Evidence

[97] Dr Mark Levy's Evidence

[98] Professor Andrew Bush's Evidence

[99] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report]* (May 2014) Pg. xii.

[100] Great North Children's Hospital's Evidence

[101] Dr Mark Levy's Evidence

Asthma Management In The UK:
Long-Term Control Medications

Support for the standard asthma medication of preventative inhalers such as low dose Inhaled Corticosteroids (ICS) in combination or without Long Acting Bronchodilators (LABA) is widespread among respondents[102, 103, 104] and the Primary Care Respiratory Society told us that 'low dose ICS is the foundation of asthma management.'[105]

We discovered however, that the usage of higher dose (or long-term low dose) oral steroids is causing widespread concern, while others[106] noted the dangers of corticosteroid over-use. The extended use of OCS has been noted as causing damaging side effects such as osteoporosis, hypertension, obesity, type 2 diabetes, gastrointestinal ulcers/bleeds, fractures, and cataracts.[107]

Asthma UK/BLF stated that 'now that we finally have specialist services and biologic treatments, frequent OCS prescriptions are no longer a justifiable treatment option and should be seen as a failure of care that should trigger a referral.'[108]

As an alternative to the use of OCS, greater use of biologics in asthma treatment was widely supported by respondents including the ARNS,[109] Professor Ian Pavord,[110] the Yorkshire Asthma MDT[111] and are compared favourably to OCS by Asthma UK/BLF.[112] Patients Gabby Perry[113] and Poppy Hadkinson[114] expressed concerns around the lack of awareness of the suitability of biologics, for some patients, among clinicians.[115] Overall, our respondents strongly supported the use of biologics as an effective treatment for severe asthma for appropriate patients.

We recommend that clinicians be supported in their choice to prescribe biologics to severe asthma patients with adequate funding to support biologics services and wider education on the benefits of this form of treatment.

"The usage of higher dose (or long-term low dose) oral steroids is causing widespread concern"

[102] PCRS's Evidence

[103] Asthma UK Centre for Applied Research's Evidence

[104] Professor Andrew Bush's Evidence

[105] PCRS's Evidence

[106] Asthma UK and British Lung Foundation's Evidence

[107] Asthma UK and British Lung Foundation's Evidence

[108] Asthma UK and British Lung Foundation's Evidence

[109] Association of Respiratory Nurse Specialists' Evidence

[110] Professor Ian Pavord's Evidence

[111] Yorkshire Asthma MDT's Evidence

[112] Asthma UK and British Lung Foundation's Evidence

[113] Gabby Perry's Evidence

[114] Poppy Hadkinson's Evidence

[115] Dr Binita Kane (North West Severe Network)'s Evidence

Patient Pathway:
Primary Care

The majority of asthma cases are managed and treated within the primary care system, although we heard of a number of challenges for asthma management and treatment within primary care.

There is no standard recognised diagnostic test for asthma and testing can therefore result in incorrect and/or delayed diagnosis which can have a severe effect on patients' lives.

There are a number of tests used to help diagnose asthma in primary care, such as:

- FeNO test – measures the level of nitric oxide in the breath, which is an indicator of inflammation in the lungs
- Spirometry – measures the speed of exhalation and how much air can be held in the lungs
- Peak flow test – also measures speed of exhalation. This test may be repeated over to identify changes over time

In addition to these tests, Asthma UK/BLF has called for investment into the development of a low-cost, accurate diagnostic test that improves diagnosis in primary care and identification of new biomarkers.[116]

Asthma UK/BLF suggested that every asthma patient should receive three basic elements of asthma care, which would contribute to helping people with asthma self-manage their condition and stay out of hospital. We note that these measures are recommended in the BTS guidelines and endorsed by NICE.

The three basic elements:

- an asthma review, depending on clinical need or severity
- having an inhaler technique check
- having a written asthma action plan

Their 2019 Annual Survey found that 60.5%, equating to 3.27 million people in the UK are not receiving the most basic level of asthma care. We find this unacceptable and call on the government to take effective steps to ensure that this is corrected.

We recommend that the guideline discussions being undertaken by NICE, BTS and SIGN should consider these three elements of patient-centric best practice and the BTS care bundle with a view to incorporating the critical elements into routine clinical practice

The Asthma UK Centre for Applied Research told us that a lack of resources within primary care made it difficult to free up primary care appointments for post-discharge reviews at short notice, and capacity issues compounded this further.[117] They also pointed to a perceived lack of importance of follow-up treatment once symptoms have been resolved, which may also impact the number of patients receiving follow-up appointments within two working days.[118]

Short-course OCS are often seen as the "answer" to an asthma flare up - and usually are, as they treat the flare-up. However, a post-discharge review should ascertain the underlying reason for the flare-up, with optimisation of current treatment (technique and adherence) to prevent further flare-ups (and admissions).

[116] Asthma UK, *Diagnosing Asthma: a 21st Century Challenge* (2017) https://www.asthma.org.uk/globalassets/get-involved/external-affairs-campaigns/diagnostics/diagnosing-asthma-21st-century-challenge.pdf [Last accessed 16th November 2020]

[117] Asthma UK Centre for Applied Research's Evidence

[118] Asthma UK Centre for Applied Research's Evidence

The Centre is currently undertaking a UK-wide trial, ARRISA-UK[119] which will consider flagging 'at-risk patients' in primary care records. Under the trial, integrated digital health systems would enable the flagging of records to be shared with out-of-hours services and emergency departments. We await the outcomes of the study with considerable interest.

We were impressed by the evidence we received from BREATHE on the effective use of NHS data. They stated in their evidence that the use of routine data is underutilised or even used inaccurately.[120] They felt that although the UK is in a good position in terms of the wealth of health data available, a large proportion of the data are still not being used to optimise care.[121]

They stated that differences in information systems prevent clinicians in primary or secondary care accessing a complete patient record that results in fragmented, inconsistently structured data which can be cumbersome to access, despite having some of the most detailed respiratory datasets in the world.[122]

We recommend that the Government looks more fully into the possibilities of NHS data being made more widely available and allowing them to be interpreted by clinicians to improve asthma outcomes in clinical practice.

We recommend that the Government adopts a consistent and practical electronic health record for asthma, which can be shared across primary and secondary care (including urgent care). We also recommend that the NHS undertakes a specific assessment of innovative technologies that may be of most help to asthma patients.

There was a wider call from a number of responders for greater coordination between specialist and generalist clinicians, who suggested that there is good evidence that a strong relationship between GPs and asthma specialists yields effective results in controlling asthma. The French study 'Management of asthma in patients supervised by primary care physicians or by specialists' (2006)[123] found 52.2% of asthma patients in a group supervised by specialists were properly controlled, as opposed to only 26.4% of patients in a group supervised solely by GPs.

The study recommended the improvement of care coordination between GPs and specialists, an approach that fits the Swedish model of accrediting asthma care clinics within practices, without which clinics would not be permitted to provide asthma or COPD care.[124]

We also note that NICE recommends in its asthma guideline, that those responsible for planning diagnostic service support to primary care (for example, clinical commissioning groups) should consider establishing diagnostic hubs to achieve economies of scale, enable earlier diagnosis of asthma and severe asthma, guide effective management and improve the practicality of implementing the recommendations in this guideline.

There was considerable support for this from our experts and we believe that it should be rolled out further across the country.

We recommend that the Government puts in place the necessary steps for the creation and roll out of diagnostic hubs for respiratory illnesses, including asthma, throughout primary care.

[119] J. R. Smith, S Musgrave, E Payerne. *At-risk registers integrated into primary care to stop asthma crises in the UK (ARRISA-UK): study protocol for a pragmatic, cluster randomised trial with nested health economic and process evaluations.* Trials, 19, 466 (2018) https://abdn.pure.elsevier.com/en/publications/at-risk-registers-integrated-into-primary-care-to-stop-asthma-cri [Last accessed 18th October 2020]

[120] Trung N. Tran, Elizabeth King, Rajiv Sarkar, et al. *Oral corticosteroid prescription patterns for asthma in France, Germany, Italy and the UK.* European Respiratory Journal 2020 55: https://erj.ersjournals.com/content/55/6/1902363 [Last accessed 16th October 2020]

[121] BREATHE's Evidence

[122] BREATHE's Evidence

[123] L Laforest , E Van Ganse, G Devouassoux et al, *Management of asthma in patients supervised by primary care physicians or by specialists* Eur Respir J 2006 Jan;27(1):42-50. doi: 10.1183/09031936.06.00035805. https://pubmed.ncbi.nlm.nih.gov/16387934/ [Last accessed 16th October 2020]

[124] Dr Dermot Ryan's Evidence

Patient Pathway:
Secondary Care And Emergency Admissions

The SIGN/BTS guidelines state that uncontrolled asthma is a risk factor for near fatal asthma and describe this as asthma that has an impact on a person's lifestyle or restricts their normal activities.[125] Symptoms such as coughing, wheezing, shortness of breath and chest tightness associated with uncontrolled asthma can significantly decrease a person's quality of life and may lead to a medical emergency.[126]

The guideline uses three pragmatic thresholds to define uncontrolled asthma:[127]

- 3 or more days a week with symptoms or
- 3 or more days a week with required use of a SABA for symptomatic relief or
- 1 or more nights a week with awakening due to asthma

The BTS/SIGN guidelines identify five key risk factors:[128]

- previous near-fatal asthma
- previous admission for asthma, especially if in the last year
- requiring three or more classes of asthma medication
- heavy use of SABA
- repeated attendances at A&E for asthma care, especially if in the last year

The NICE guideline also calls on HCPs to take a number of other factors into account before starting or adjusting asthma medication.[129] These include:

- alternative diagnoses
- lack of compliance
- suboptimal inhaler technique
- smoking (active or passive)
- occupational exposures
- psychosocial factors
- seasonal or environmental factors

For some patients, asthma attacks require emergency care, and hospital admission, with "mild" asthma patients suffering twice as many asthma attacks if prescribed ≥3 SABAs.

Hospital admissions (2012) for asthma in adults in the UK are amongst the highest across the major European countries[130] with an estimated 77,000 hospital admissions each year[131] due to asthma exacerbations.

High asthma hospitalisation rates also show up the health inequalities within the UK, with the Association of Chartered Physiotherapists in Respiratory Care (ACPRC) noting that 'those living in more deprived areas of England are more likely to go to hospital for their asthma'[132]

[125] NICE. *Asthma: diagnosis, monitoring and chronic asthma management: NICE guideline [NG80],* Recommendations.

[126] NICE. *Asthma: diagnosis, monitoring and chronic asthma management: NICE guideline [NG80],* Recommendations.

[127] NICE. *Asthma: diagnosis, monitoring and chronic asthma management: NICE guideline [NG80]* Recommendations.

[128] BTS/SIGN British guideline on the management of asthma, a national clinical guideline. https://www.sign.ac.uk/media/1773/sign158-updated.pdf [Last accessed November 2020]

[129] NICE. *Asthma: Diagnosis, Monitoring and Chronic Asthma Management: NICE guideline [NG80]* Recommendations.

[130] European Respiratory Society. *European Lung White Book.* Chapter 12: Adult Asthma (2019)

[131] Asthma UK. Asthma Stats and Figures. https://www.asthma.org.uk/about/media/facts-and-statistics [Last accessed 16th October 2020]

[132] Association of Chartered Physiotherapists in Respiratory Care's Evidence

Those patients who are hospitalised tend to be younger, with patients aged 18-29 more than twice as likely to receive emergency care as opposed to those aged over 60,[133] although the majority of asthma deaths are in those over 65. Patients aged 18-29 also have the highest level of uncontrolled asthma of all age groups.[134] This has led groups such as AUKCAR[135] and the ACPRC[136] to call for greater focus on asthma treatment adherence rates among younger people.

Asthma UK/BLF advised us that follow-up after emergency care is vital to prevent hospital readmission as patients need a review for the exacerbation to understand why it occurred and prevent it from escalating again, but for most people with asthma this is not happening.[137]

They also claimed that no one is accountable for ensuring follow-up due to poor collaboration between secondary and primary care, although it is a recommendation within NICE Quality Standard number 4.[138]

NRAD recommended that follow-up arrangements must be made after every attendance at an emergency department or out-of-hours service for an asthma attack.[139] This is reinforced by both NICE[140] and BTS/SIGN[141] guidelines which recommend a two-day follow-up period. This was further reinforced in the submission from the ACPRC.[142]

NRAD also analysed patient deaths and found that 47 per cent had a history of previous hospital admission,[143] and 10 per cent died within 28 days of discharge.[144]

Asthma UK's 2018 survey found that 64 per cent of admitted patients did not receive a primary care follow-up within two days[145] and that 65 per cent should have had.[146]

Emergency admissions and the lack of adequate follow up were of considerable concern for us and we note that although the need for a follow up within two days was consistent in the evidence we received and is a shared recommendation in the various guidelines, this was not happening consistently.

We recommend that when clinically agreed thresholds have been reached on repeat prescriptions and on the use of relief inhalers and courses of OCS, health records should be used as an automatic trigger for reviews, follow up appointments and referrals.

The AUKCAR recommended increased continuity in care to improve the lack of effective communication between the care levels.[147] They gave practical examples in their submission including a clear flowchart pathway handed out to patients during an emergency asthma care event regarding a follow-up appointment. Better education of primary care professionals about this pathway and communication to GPs regarding attendance in emergency departments should be improved, particularly for patients attending emergency departments outside of their GP area.

[133] Association of Chartered Physiotherapists in Respiratory Care's Evidence

[134] Asthma UK. *The Great Asthma Divide: The Annual Asthma Survey 2019.* Pg. 16 https://www.asthma.org.uk/58a0ecb9/globalassets/campaigns/publications/The-Great-Asthma-Divide.pdf [Last accessed 16th October 2020]

[135] A De Simoni. R Horne. L Fleming. *What do adolescents with asthma really think about adherence to inhalers? Insights from a qualitative analysis of a UK online forum* BMJ Open, 7 (2017) https://bmjopen.bmj.com/content/7/6/e015245 [Last accessed 16th October 2020]

[136] R C Kosse, M L Bouvy, T W de Vries. *Effect of a mHealth intervention on adherence in adolescents with asthma: A randomized controlled trial.* Respir Med 2019 Mar; 149:45-51. https://pubmed.ncbi.nlm.nih.gov/30803885/ [Last accessed 16th October 2020]

[137] Asthma UK Centre for Applied Research's Evidence

[138] NICE. *Asthma: Diagnosis, Monitoring and Chronic Asthma Management: NICE Guideline [NG80],* Quality statement 4: Follow-up by general practice after emergency care. [Last updated: 20th September 2018] https://www.nice.org.uk/guidance/qs25/chapter/Quality-statement-4-Follow-up-by-general-practice-after-emergency-care [Last accessed 18th October 2020]

[139] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report],* Pg xi.

[140] NICE. *Asthma: diagnosis, monitoring and chronic asthma management: NICE guideline [NG80],* Quality statement 4: Follow-up by general practice after emergency care

[141] BTS/SIGN. *SIGN 158 British Guideline on the Management of Asthma: Quick Reference Guide.* Pg. 18.[Last updated: July 2019]

[142] Association of Chartered Physiotherapists in Respiratory Care's Evidence

[143] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report],* Pg. x

[144] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report],* Pg. x

[145] Asthma UK, *The Reality of Asthma Care in the UK: Annual Asthma Survey 2018 Report.* (2019) Pg.4

[146] Asthma UK, *The Reality of Asthma Care in the UK: Annual Asthma Survey 2018 Report.* (2019) Pg.4

[147] Asthma UK Centre for Applied Research's Evidence

Other suggestions from our respondents included more effective use of digital health especially if a red flag system could be introduced to highlight emergency care on patient records[148] and video consultations with the practice nurse for both young adults and adults.[149]

Asthma UK/BLF also suggested, in response to our direct question, that QOF may be an appropriate mechanism to incentivise primary care to ensure patients are reviewed within two days of receiving emergency care.[150] Follow up and reviews need to be done to minimise the exacerbations and this needs to be reflected in the asthma QOF.[151]

We consider that there are two crucial roles for QOF which would improve asthma outcomes – to incentivise primary care to ensure patients are reviewed within two days of receiving emergency care, by someone trained to do so and prevent the overuse of reliever inhalers by clearly defining thresholds to trigger follow-up action and improve adherence to preventative medication.

We recommend that QOF should be used to incentivise high quality outcomes for asthma, both in terms of improved quality of life as well as reduced asthma attacks, admissions and deaths.

"We recommend that when clinically agreed thresholds have been reached on repeat prescriptions and on the use of relief inhalers and courses of OCS, health records should be used as an automatic trigger for reviews, follow up appointments and referrals.

[148] Asthma UK Centre for Applied Research's Evidence

[149] Asthma UK Centre for Applied Research's Evidence

[150] Asthma UK and British Lung Foundation's Evidence

[151] Asthma UK and British Lung Foundation's Evidence

Patient Pathway:
Specialised Care (England)

There are 12-14 main directly commissioned centres for specialist asthma care in England and patients suffering from chronic asthma which is not responding to treatment and severe asthma patients should be referred to these centres. A number of our respondents raised concerns over their capacity,[152] the number and distribution of centres[153, 154] and the criteria for referral to the centres.

Implications of COVID-19 and social distancing may impact the ability of the centres to cope with the number of referrals further. Cleaning consulting rooms after each patient and social distancing measures may lead to increased waiting lists and impact on morbidity and other healthcare services.

"There are 12-14 main directly commissioned centres for specialist asthma care in England and patients suffering from chronic asthma which is not responding to treatment and severe asthma patients should be referred to these centres"

[152] Dr Adel H Mansur's Evidence

[153] Cheryl Seymour's Evidence

[154] Martin Allen's Evidence

Severe Asthma And Referral

There is no single test that can be used to diagnose severe asthma. Diagnosis can normally only be undertaken in specialist-led centres, which have the appropriate clinical expertise and access to specialist diagnostic equipment, not currently seen in general practice.

In the UK up to 250,000 people have asthma so severe that it does not respond to existing high dose inhaled and adjuvant treatments,[155] which can result in multiple and repeated trips to hospital, sometimes as an emergency.[156]

It was clear from the evidence that we don't know the exact number of severe asthma patients, nor the number that are being treated within the NHS or even how long the waiting list is. Asthma UK/BLF estimates that there are up to 250,000 severe asthma patients in the UK,[157] with up to 137,500 being treated in primary care, 87,500 in secondary care and only 25,000 (10%) being treated in tertiary care (England only). Of these, only 10% are being treated with biologics. Although there is a BTS Severe Asthma Registry, this does not include all areas of the UK.

To add to the uncertainty, in a recent question in Parliament, the Minister was asked what plans they had to centrally collate data on the total number of severe asthma patients. The answer was that there are no plans for this,[158] although it is estimated that these patients account for 50% of asthma costs.

Our respondents noted that NICE, BTS/SIGN, GINA and NRAD guidelines all give similar criteria for referring a patient to a specialised asthma centre.

Specialised asthma centres are seen as crucial for the treatment of severe asthma in particular, with the BTS stating: 'Raising awareness on severe asthma, earlier diagnosis of severe asthma and better identification of the severe asthma patient is being driven by clinicians from nationally commissioned severe asthma centres'.[159] Many respondents supported making access to the centres simpler for severe asthma patients.

NHS England specifies that patients with severe asthma need to be considered as a separate group from the majority of people with mild to moderate disease. Those with severe asthma require systematic assessment and specialist care in tertiary respiratory centres.[160]

However, Asthma UK research suggests that 82% of difficult and severe asthma patients are often not being referred at the right time, or sometimes, not at all.[161]

In patients diagnosed with asthma who are using preventer and reliever treatments as prescribed and whose symptoms haven't improved sufficiently, a GP or asthma nurse will consider additional indicators for a severe or difficult to control asthma referral such as:[162]

- Use of reliever inhaler three or more times per week
- A 3-day or longer course of steroid tablets for two or more times in the past year
- Requiring steroid tablets every day to control asthma symptoms
- The number of A&E visits and hospital stays in the past year
- Impact of asthma symptoms on daily life – for example: sleep deprivation, time off work or impact on social life
- Use and impact of preventer medicines – if they help to control their asthma symptoms with or without side effects

[155] Asthma UK, *Severe Asthma: The Unmet Need and the Global Challenge* (2017) Pg. 3 https://www.asthma.org.uk/globalassets/get-involved/external-affairs-campaigns/publications/severe-asthma-report/auk_severeasthma_2017.pdf [Last accessed 18th October 2020]

[156] Asthma UK, *Severe Asthma: The Unmet Need and the Global Challenge* (2017) Pg. 3

[157] Asthma UK, *Severe Asthma: The Unmet Need and the Global Challenge* (2017) Pg. 3

[158] WPQ 85020, 22nd September 2020

[159] British Thoracic Society's Evidence

[160] NHS England. NHS Service Specifications. *Specialised Respiratory Services (adult) – Severe Asthma Specification (170002/S)* (2017)

[161] Asthma UK, *Living in Limbo: the Scale of Unmet Need in Difficult and Severe Asthma.* (2019) Pg. 11

[162] BTS/SIGN. *SIGN 158 British Guideline on the Management of Asthma.* Pg. 90. [Last updated: July 2019] https://www.brit-thoracic.org.uk/quality-improvement/guidelines/asthma/ [Last accessed 18th October 2020]

However, we note that some of these criteria are also prevalent in normal asthma patients with poor compliance with their existing medication.

BTS/SIGN guidelines state that over prescription of inhaled and/or oral steroids and symptoms of acute severe or life-threatening asthma are criteria for referral. (46) NRAD recommends that patients should be referred to specialist asthma services if they have required more than two courses of systemic corticosteroids in the previous 12 months.[163]

Long term use of OCS was of concern to most of our responders and Asthma UK's 2019 report on severe asthma identified over 130,000 patients on three or more OCS courses over the course of 12 months[164] with only 23.4% being referred,[165] which means that they have had multiple asthma attacks but have still not been referred according to the guidelines.

Long term use of OCS is also associated with a risk of side effects including mood changes, bone weakening and weight gain.[166, 167, 168]

We agree with the experts that referrals for severe asthma can take too long and they should not be seen as a last resort - the referral process needs to be quicker or it will fail for those patients who need it most. We cannot see this being easily resolved without strong, commonly agreed guidelines and system incentives to identify and refer patients.

We agree with the BTS that raising awareness of severe asthma and its earlier diagnosis and better identification of the severe asthma patient should be driven by clinicians from nationally commissioned severe asthma centres.[169]

Asthma severity is rarely coded in GP records. All asthma patients seen in secondary care should have the severity classified and GPs should then code this in their records to ensure that all patients with severe asthma are referred to severe asthma specialists.

Asthma UK/BLF pointed to a lack of joined up data and different systems between primary and secondary care which results in GPs being unaware of the admission of their patients and the consequential lack of an appropriate follow-up. They also suggested that more needs to be done to identify high-risk patients through better data coding for asthma attacks, hospital admissions, medication and OCS use.

They suggested a single electronic health record that captures all patient data, facilitating effective information sharing when someone with asthma is being seen in different health settings. This can then be automatically flagged to a local GP and an appointment can be booked within two days, ensuring a more joined-up and integrated follow-up process.

We also note that there is currently no severe asthma coding and it has been suggested that there should be an appropriate clinical code for severe asthma.

We agree with our experts that these common sense steps will make a material difference to the speed and appropriateness of referrals.

We recommend that an appropriate clinical code needs to be created for severe asthma, to give certainty to patients and clinicians

[163] Royal College of Physicians & Health Quality Improvement Partnership, *Why Asthma Still Kills: The National Review of Asthma Deaths [confidential enquiry report]* Pg. xi.

[164] Asthma UK, *Living in Limbo: the Scale of Unmet Need in Difficult and Severe Asthma* (2019) Pg. 10

[165] Asthma UK, *Living in Limbo: the Scale of Unmet Need in Difficult and Severe Asthma* (2019) Pg. 12

[166] Asthma UK and British Lung Foundation's Evidence

[167] Asthma UK, *Severe Asthma: The Unmet Need and the Global Challenge* (2017) Pg. 3

[168] Dr Dermot Ryan's Evidence

[169] BTS's Evidence

UK Asthma Guidelines

As of 2020, there are currently several asthma guidelines used throughout the UK. These include the guidelines created by NICE, BTS/SIGN, GINA and the Primary Care Respiratory Society (PCRS), as well as locally-developed guidelines.

The coexistence of multiple guidelines and the challenges of implementing the various conflicting clinical guidelines in practice is noted as an unnecessary complication within British asthma care by an overwhelming number of our respondents[170, 171, 172] with many singling out the confusion caused by having varying guidelines with none being given priority by governmental or clinical bodies.[173, 174] The varying guidelines were also seen as causing delays in treatment, variation in patient diagnosis and differences in treatment.[175]

The respondents overwhelmingly welcomed the planned merger of the NICE and BTS/SIGN guidelines into the UK-wide Joint Guidelines on Chronic Asthma. We also welcome the moves being made to rationalise the various guidelines, with the BTS stating that the work needed to bring about the combination of the two guidelines will continue this year.[176] Although we do not expect a joint outcome until some time in 2021, this is a positive step forward.

We recommend that the government drives and monitors greater uniformity and consistency in the asthma guidelines and that they undertake a 12-monthly review of the new revised guidelines which are expected from the NICE/BTS/SIGN discussions in 2021.

"We recommend that the government drives and monitors greater uniformity and consistency in the asthma guidelines"

[170] Dr Dominic Shaw's Evidence

[171] Yorkshire Asthma MDT's Evidence

[172] Dr Abel H Mansur's Evidence

[173] Yorkshire Asthma MDT's Evidence

[174] Dr Abel H Mansur's Evidence

[175] PCRS's Evidence

[176] BTS's Evidence

Conclusion

It is clear from the evidence provided throughout the inquiry that asthma and severe asthma represent significant challenges for clinicians and patients throughout the UK. The lack of consistency in the guidelines has been reflected, as a consequence, in variation in referrals for difficult to treat asthma.

We were enormously impressed by the quantity and breadth of research and work that is being undertaken by so many individuals and organisations and the professionalism, dedication and commitment by all the stakeholders who replied to our inquiry. We commend their work and the positive steps that have been taken throughout the clinical pathways to improve patients' lives and the lives of their families and carers.

We congratulate the leadership that is being shown by Professor Andrew Menzies-Gow as the NHS England and Improvement National Clinical Director and the determination that is being shown across the clinical community to improve asthma outcomes.

We also commend the work done by the government and ministers in declaring respiratory illnesses a policy priority and we hope that the implementation of the Long Term Plan and other initiatives will continue to prioritise respiratory health in general and asthma in particular.

That is not to say that there are no difficulties. Our respondents identified a number of individual problems which we have referred to extensively – conflicting guidelines; variations in primary care delivery, particularly around referrals and follow-up reviews; a disconnect in some circumstances between primary and secondary care; a lack of data availability, over-reliance on reliever inhalers and oral corticosteroids; variation in clinical responsibility for individual patients and difficulties and delays in identifying and managing severe asthma.

While our recommendations cover all these issues, the success of future asthma care will require ongoing cooperation within the clinical community.

We conclude that small changes will make large impacts for patients' lives and many of the stakeholders who contacted us have already begun the process of making this happen. It is vital that the asthma community continues to expand research and work together to improve the current health systems, to improve asthma outcomes and to save lives.

"We conclude that small changes will make large impacts for patients' lives and many of the stakeholders who contacted us have already begun the process of making this happen"