International Primary Care IPCRG Respiratory Group

EFA

POSITION PAPER

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Ten easy steps to defeat difficult-to-manage asthma

What action would you take to stop 10 jumbo jets crashing every week of the year, to prevent the deaths of nearly 700 people on board each time, when regular systematic checks of each aircraft could virtually eliminate the problem?

This is the current situation for **asthma**. We sometimes think that asthma is largely well controlled, with effective treatments available and evidence-based guidelines supporting careful diagnosis and good patient care. But ongoing symptoms and deaths due to inadequately controlled asthma and the associated high costs to both the people affected, to their families, and to healthcare services alert us to the fact that more action is urgently needed to improve the care of people with asthma, and in particular those whose asthma is **difficult to manage**.

Difficult-to-manage asthma is asthma that either the person affected or the clinician finds difficult to manage. This includes people:

- with severe asthma, whose asthma remains uncontrolled despite best treatment: a considerable number of these have other diseases which may be amenable to treatment
- who – for various reasons – don't take their treatment as recommended
- with other conditions affecting their asthma, including allergy, other diseases and psychological factors.

The World Health Organization (WHO) estimates that 235 million people worldwide suffer from asthma.[1] Approximately 250,000 deaths are attributed to asthma each year – which is nearly 685 each day.[2,3] Most of these occur in people aged 45 and older and are largely preventable, often related to inadequate long-term medical care.[4] The recent World Health Survey found that half of people with clinical or treated asthma reported wheezing in the last 12 months and 20% had never been treated for asthma.[5]

What does it feel like to have difficult-to-manage asthma?

"Asthma is just something I accept and manage day-to-day." Trevor Keegan is a TV presenter on RTE (Ireland)'s Afternoon Show. He was diagnosed with asthma when he was five and always told he would grow out of it. "But I'm still waiting," Trevor says. When Trevor was in his 20s he really got his condition under control with the help of a new doctor. "He has been brilliant at monitoring and assessing my condition and changing my inhalers accordingly.

"Asthma is just something I accept and manage on a daily basis. Even bringing inhalers on holiday is just par for the course. Luckily I have only ever been hospitalised once due to asthma on the one occasion when I was away and my inhaler ran out." In terms of hosting a TV show, Trevor says episodes of worsening asthma can often be difficult to work through. "They can make you feel tired and drained which is not an option when you present the afternoon show on Fridays. Live TV can be very unforgiving if you don't keep your eye on the ball at all times."

Ten easy steps

The good news is that ten easy steps can go a long way to reducing the human and health service costs of difficult-to-manage asthma. They make it easier for healthcare professionals and people with asthma to do the right things in the right way to improve asthma control.

- Target difficult-to-manage asthma as a priority for improving value and equity of healthcare
- Strengthen and support primary and community health services and improve interaction with hospital services for asthma
- Introduce a national asthma plan and include difficult-to-manage asthma
- Provide access to tests for diagnosing asthma and respiratory allergies supported by training in diagnostic testing and interpretation of results for GPs and nurses
- Empower people with difficult-to-manage asthma to self-manage their condition
- Reimburse annual structured reviews in primary care for people with asthma
- Support research that helps to answer questions about effective prevention strategies, the impact of other diseases on asthma, how to promote adherence to optimal treatment by both professionals and patients and advanced patient-centred care that helps people "co-manage" or self care
- Support systematic and shared data collection on difficult-to-manage asthma
- Include difficult-to-manage asthma in tobacco control policies
- Develop policies that reduce the impact of environmental factors on asthma at home, work and more widely.

Target difficult-to-manage asthma as a priority for improving value and equity of healthcare

Asthma is currently a very costly condition to individuals affected and to healthcare systems and societies as a whole, and improving its management in primary care offers a highly effective way to improve value and equity of healthcare. According to the World Health Organization (WHO), the estimated economic costs associated with asthma exceed those of tuberculosis (TB) and HIV/AIDS combined.[6]

- In the United States annual asthma care costs (direct and indirect) exceed US$6 billion.[6]
- The UK spends about US$1.8 billion on health care for asthma and because of days lost through illness.[6]
- In Australia, annual direct and indirect medical costs associated with asthma reach almost US$460 million.[6]

Improving the care of people with difficult-to-manage asthma by providing services such as better primary care management and more efficient referral of patients needing a multidisciplinary difficult-to-manage asthma service is a good way to provide value (patient-centred outcomes divided by the cost of delivering those outcomes).[7] Outcomes include fewer avoidable hospital admissions and asthma deaths and improved quality of life for patients at the cost of the right service provision and appropriate prescribing.

There are good cost arguments for improving the care of difficult-to-manage asthma. Uncontrolled asthma is more costly than controlled asthma.[8] A cost-effectiveness study of a Brazilian public health intervention for severe asthma in Salvador showed the health-related annual costs of one patient with severe asthma is 750 US$ for the Public Health System and 807 US$ for their families (almost one-third of median total family annual income).[9] The programme reduced morbidity, improved quality of life and saved resources for the health system and patients' families, achieving a rapid reduction in asthma admissions to hospital.[10,11]

A 10-year national programme in Finland (1994-2004) provided clear evidence of the value of introducing a nationwide community-based programme to improve the management of asthma in reducing the costs of asthma and the impact on individuals. Over ten years, the costs per patient per year decreased by 36% (from €1611 to €1031) and the number of patients' hospital days fell by 54%, in addition to an 80% reduction in deaths, 85% reduction in hospitalisations and 60% reduction in disability pensions in people of working age related to asthma.[12]

Small changes achieved by better care can transform people's lives. Breda Flood, a retired headteacher living in Ireland, has had asthma for 15 years but suffered wheeziness throughout last winter. She sought help and her doctor suggested she used a spacer – a plastic cylinder attached to the inhaler that delivers medicine to the lungs more effectively and makes it easier to use an asthma inhaler – and she immediately found her asthma symptoms improved.

Improving value can also reduce variation and inequalities. Recent figures showed an 11-fold difference in hospital admission rates for asthma between countries with the highest rates and those with the lowest.[13] The United States, the Slovak Republic and Korea all had rates around double the OECD average. A systematic approach to managing asthma improves access to best quality care for all. 90% of COPD as well as most asthma-related deaths occur in low- and lower-middle income countries.[1] This is mainly due to the differences existing in access to healthcare and the quality of the care being provided.

Strengthen and support primary and community health services and improve integration with hospital services for asthma

The World Health Assembly has adopted a global target of a 25% reduction in premature mortality from non-communicable diseases by 2025 including chronic respiratory diseases.[14,15] Strengthening primary and community care is recognised as a core element in any national plan to address non-communicable disease, and asthma is a common non-communicable disease. Therefore, investment in strengthening primary care is needed, both in terms of sponsorship (in its non-financial senses of endorsement and interest) and reimbursement. Community-based healthcare services should be supported to take a central role in the care of people with difficult-to-manage asthma. This includes ensuring essential medicines for asthma are available and affordable, and can be prescribed in primary care.

The Finnish National Asthma Programme showed that shifting care from specialist to primary care was effective in achieving a major reduction in the morbidity and costs associated with asthma.[12]

Value is patient health outcomes per dollar spent (Value = Health outcomes / Costs of delivering the outcomes):

- Outcomes are the **health results that matter for a patient's condition** over the care cycle. For people with difficult-to-manage asthma, these are: improving quality of life by reducing cough and wheeze and reducing severe asthma attacks that can result in hospitalisation and are sometimes fatal.
- Costs are the **total costs of care for a patient's condition** over the care cycle. For people with difficult-to-manage asthma, these include both direct costs to the healthcare system such as hospitalisation, emergency room visits, visits to the doctor, homecare and medicine and broader societal costs such as not being able to work or attend school or college.

Asthma outcomes should be measured across three tiers:

- First: reduce mortality and improve survival
- Second: improve recovery after an asthma attack and the cost of healthcare disutility
- Third: the quality and time a person with asthma is well controlled minus the time and quality of side-effects of therapies.[7]

Asthma management should be integrated vertically between community and hospital care – using shared guidelines, goals and language (including coding) and led by clinicians who want to ensure best outcomes for patients working in partnership with patients and their families. Improving asthma services in primary care to provide a systematic approach to managing people with difficult-to-manage asthma will require a systematic peer-led education programme (a train the trainer programme provides a cost-effective approach) and disseminating and ensuring facilitation of guidelines written for primary care by primary care.

Primary care professionals should also have access to clinics with experience in difficult-to-manage asthma for the patients they identify require specialist assessment and care. These clinics should provide care by a multidisciplinary team including respiratory physicians, specialist nurses, psychologists and relevant physicians for co-morbidities and have access to the full range of diagnostic and assessment tools and treatments. Pharmacists need to be included for monitoring and improvement of the daily use of prescribed medication. ▶

A recent audit of a centralised respiratory diagnostic service for primary care showed this reduced the risk of misdiagnosis and mistreatment of respiratory conditions[15,16] but these services are not widely available: a UK survey showed that only 23% of respiratory physicians had a dedicated difficult asthma clinic in their hospital.[17] See http://www.theipcrg.org/difficultasthma for an example of an ideal referral letter from primary care to a specialist service.

Introduce a national asthma plan and include difficult-to-manage asthma

Without a national asthma plan, the healthcare system will not generate the value that it is capable of achieving. National guidelines and policies should provide guidance and set targets for healthcare providers to keep registries of people with asthma, and to reduce emergency healthcare use, hospitalisations and days off work or school experienced by people with difficult-to-manage asthma. To achieve this they should encourage health care professional use of tools/instruments to assess an individual's asthma control and, if necessary, their reasons for poor control.

Provide access to tests for diagnosing asthma and respiratory allergies supported by training in diagnostic testing and interpretation of results for GPs and nurses

Primary care professionals should have access to and sufficient training on the use of evidence-based tests for asthma such as peak flow measurement and spirometry, which should be reimbursed as part of making an initial diagnosis of asthma and in reviewing a patient with difficult-to-manage asthma.

Where a respiratory allergy is suspected that may affect a patient's asthma control, primary care professionals should have access to regulated allergy testing and appropriate evidence-based treatment. This will normally require referral to secondary care given the lack of allergy testing in primary care. Data collected by the European Federation of Allergy and Airway Diseases Patients Association (EFA) shows that approximately 30% of the European population suffers from respiratory allergies.[18] Recent figures show that 113 million EU citizens suffer from allergic rhinitis and 28 million from allergic asthma but approximately 45% of people with respiratory allergies have never received a diagnosis of respiratory allergy.[18] Up to 80% of people with asthma have a respiratory allergy.[18]

Empower people with difficult-to-manage asthma to self-manage their condition by commissioning national information co-created by patient groups and clinicians and incentivising healthcare professionals to develop action plans with their patients

In addition to spoken information, people with difficult-to-manage asthma should be given written and/or picture and video information by their healthcare professional that is personalised to their needs to help them to self-manage their condition. Asthma patient groups should be involved in the preparation of materials, which should be easy to understand and provide practical recommendations.[19,20]

Strategies should take a patient-centred approach, putting the person with asthma at the centre of all efforts to improve their health and wellbeing and considering the whole person (and their family, where appropriate) and not just their asthma. Patients should be clear about when and how to access health services and feel confident they will provide the support and care they need.[21,22,23]

[Roberts NJ, Mohamed Z, Wong PS, Johnson M, Loh LC, Partridge MR. The development and comprehensibility of a pictorial asthma action plan. *Patient Educ Couns* 2009; **74**(1): 12-18.
Roberts N, Evans G, Blenkhorn P, Partridge M. Development of an electronic pictorial asthma action plan and its use in primary care. *Patient Educ Couns* 2010; **80**(1):141-146
http://www.longalliantie.nl/images/library/pdf/LAN%20Zorgstandaard%20COPD-8.pdf
http://www.astmafonds.nl/bestellen/patientenversie-zorgstandaard-copd
A similar standard of care for asthma is currently being developed by the Lung Alliance Netherlands – http://www.longalliantie.nl/zorgstandaard-astma]

Reimburse annual reviews in primary care for people with asthma

If you can just do one thing, ensure that national policies reimburse structured annual reviews for people with asthma. Primary and community healthcare providers should be reimbursed for providing regular review of people with asthma to monitor their asthma control and to detect difficult-to-manage asthma early, stopping the risk that patients are simply given repeat prescriptions and never seen by a health professional. This should include a full annual review – lasting 30-60 minutes with the agenda set by the patient – that identifies when asthma control has been lost / never achieved; checks for factors causing poor control, including asking the patient to demonstrate use of their asthma inhaler(s); introduces measures to gain control; and engages the patient in maintaining long-term control. In most countries primary care providers can do this as long as appropriately resourced and incentivised for what is a time-intensive programme. Large-scale pilots are underway in some other chronic diseases that are transforming care to enable a 40-minute appointment within existing resources.[24]

Support research that helps to answer questions about effective prevention strategies, the impact of other diseases on asthma, how to promote adherence to optimal treatment by both professionals and patients and advanced patient-centred care that helps people "co-manage" or self care

Clinical trial patients are not typical of patients seen in everyday clinical practice because of strict trial inclusion criteria. Research funding should fund real-world studies conducted in primary care settings rather than hospitals that include patients from different ethnic groups, smokers and people with different asthma phenotypes. Inclusion of patients that are more typical of the average patients seen in clinics should allow a better assessment of the impact of co-morbidities and the development of strategies to promote adherence to treatment. Asthma treatment guidelines are primarily based on evidence from large clinical trials that frequently assess lung function as the primary outcome. However, inflammatory biomarker levels, asthma exacerbations and other outcomes may worsen regardless of lung function status.

The IPCRG has published a list of research questions that the international primary care community agree to be priorities.[25]

[http://dx.doi.org/10.4104/pcrj.2012.00006]

Support systematic and shared data collection on difficult-to-manage asthma

Accurate data is essential to understand the impact of difficult-to-manage asthma, to plan resources and to measure outcomes. Policies should support the systematic collection of data on difficult-to-manage asthma, including the use of common data definitions and systems across hospitals and the community that combine all types of data for each patient and allow access and communication between all sectors involved, including with patients. The World Health Organization supports surveillance and monitoring in its recent paper on noncommunicable diseases[14] and in November 2012 agreed voluntary global targets including a 25% relative reduction in overall mortality from chronic

◀ respiratory diseases, cardiovascular diseases, cancer or diabetes 2010-2025.[15]

http://apps.who.int/gb/ncds/

Include difficult-to-manage asthma in tobacco control policies

The World Health Survey of people aged 18 to 45 showed 24% of people with clinical/treated asthma were current smokers.[5] Health professionals, patients and the public should be informed about the link between smoking and poor asthma control, and supported in efforts to quit smoking and to avoid secondary smoke.[21] In the long term, a smoking ban in all public spaces and limiting smoking incidence should be the policy objective.[26, 27] In the UK, there was a fall in children's asthma admissions equivalent to 6802 fewer hospital admissions in 3 years following the introduction of the smoking ban.[28]

Policies should reduce the impact of environmental factors on asthma

Health should feature in all policies, not just health policy, and the impact on health of other policies be assessed. There is growing evidence that air pollution contributes to the global burden of respiratory and allergic diseases, including asthma.[29] Hospitalisations for asthma are increased on days of higher air pollution.[30] Indoor factors, such as moulds, house dust mite and indoor air quality and occupational air pollutants are also important in aggravating asthma.

Therefore environmental policies should reduce the impact of environmental factors on asthma, including controls on smoking, air pollution, hazards in the work place and home, as well as other environmental triggers. The healthcare system and people with asthma should be able to access easily independent and advance information on environmental factors which may affect asthma control, including pollution levels and weather, so that they can take evasive action.

How were these recommendations developed?

Ten easy steps to defeat difficult-to-manage asthma captures the key recommendations from a meeting of people working in asthma, including health professionals and a patient group representative held on 17 January 2012, organized by the International Primary Care Respiratory Group (IPCRG) that discussed the findings of an extensive review of relevant research. It addresses the management of difficult-to-manage asthma from a public health policy perspective, as well as looking at the approach required by health professionals.

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Further resources for policymakers, clinicians and people with asthma

- Holgate S, Bisgaard H, Bjermer L *et al*. The Brussels Declaration: the need for change in asthma management. *Eur Respir J* 2008; **32**: 1433-43 http://erj.ersjournals.com/content/32/6/1433.full.pdf+html doi: 10.1183/09031936.00053108
- Two-page Desktop Helper for clinicians and patients available in English, French, German, Greek, Italian, Spanish, Polish and Russian, including the mnemonic SIMPLES: smoking, inhaler technique, monitoring, pharmacotherapy, lifestyle, education and support http://www.theipcrg.org/display/DIFFMANAST/Desktop+helper+difficult+to+manage+asthma
- Ideal referral letters from primary care to a specialist service http://www.theipcrg.org/display/DIFFMANAST/Difficult+to+manage+asthma+-+Position+Paper
- Video summarising the key points including SIMPLES (due September 2013) http://www.theipcrg.org/display/DIFFMANAST/Difficult+to+manage+asthma+-+Position+Paper
- Directory of freely available Tools, Resources and Recommendations http://www.theipcrg.org/display/DIFFMANAST/Tools%2C+Resources+and+Recommendations

APPENDIX – the original Brussels Declaration

TEN POINT PLAN TO REVOLUTIONISE ASTHMA MANAGEMENT IN EUROPE

"Together we can defeat the burden of asthma."

Chaired by Professor Stephen Holgate
MRC Clinical Professor of Immunopharmacology, University of Southampton, UK

The ten key points identified in the Declaration will only make a difference if they produce real change in action with all colleagues involved in the care of people with asthma, as well as the organisations that represent their needs.

TEN POINT PLAN OF ACTION

1. Asthma must be recognised as a serious public health issue by society and asthma care should be made a political priority.
2. Policy makers and Professional Bodies, including European Patients' Associations must respond now to the developing understanding of asthma including recognition of asthma as a respiratory manifestation of systemic inflammatory processes.
3. The medical community, guided by its Professional Bodies, should also agree that asthma is different in adults, children and different ethnic groups and needs to be managed in different ways.
4. There should be an immediate update of the European Medicines Agency (EMEA) Regulatory Guidance Note on asthma, which is essential to ensure that asthma treatment and diagnosis responds to the latest scientific knowledge, clinical and real world experience.
5. Guidelines should continue to be based on clinical trial evidence, but also take into account health economic and outcomes studies that reflect 'real-world' patient care and family life, including studies that particularly address the child/infant.
6. Those responsible for funding studies at EU level must consider research which helps to answer questions about the impact of other diseases on asthma, how to promote adherence to optimal treatment by both professionals and patients and advance patient-centred care, effective prevention strategies and prevalence studies.
7. Policy makers, politicians, doctors and third parties must explore variation in asthma care across Europe and distinguish between normal variation due to differences in healthcare systems and cultures, and variation that can be reduced through policies that improve organisation of care and clinical practice.
8. National policies should incentivise the organisation of care so that patient groups and people with asthma can actively participate in and make choices about their care.
9. The EU and national governments must liaise with other agencies to understand and reduce the impact of environmental factors on asthma such as smoking, air pollution, hazards in schools, day care, the work place and home, as well as other environmental triggers.
10. National policies should set targets for healthcare providers to keep registries, reduce hospitalisations, emergency healthcare use, days off work and days off school experienced by people with asthma and encourage use of tools/instruments to assess asthma control and reasons for poor control where it exists in the individual.

Holgate S, Bisgaard H, Bjermer L *et al.* The Brussels Declaration: the need for change in asthma management. *Eur Respir J* 2008; **32**: 1433-43)