# Asthma deaths: what now?

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It is almost 50 years since the first UK studies identified potentially preventable factors in the majority of asthma deaths.[1] Those first reports led to the development of national asthma guidelines, intended to radically improve management. Since the 1980s, asthma care in the UK has shifted from secondary to primary care,[2] linked to enhanced asthma nurse training and involvement. With the development of new doctor–patient partnerships in the form of personalised self-management plans and newer drugs with innovative delivery systems, improving asthma care in the future seemed a certainty. And yet, from 1992, the only ongoing inquiry into asthma death in the East of England fuelled background concern that preventable death was still a major issue.[3] That concern was highlighted by the National Atlas of Variation in Healthcare for Respiratory Disease,[4] published in September 2012, which showed great variation in almost every facet of asthma care delivery across the UK.

The National Review of Asthma Deaths (NRAD) was a confidential enquiry that investigated in detail 900 deaths of people of all ages who had died in 2012 with an ICD-10 code J459, where the underlying cause of death was classified as asthma. It was the first national study by the Clinical Effectiveness and Evaluation Unit at the Royal College of Physicians (RCP) to span both primary and secondary care, thus providing comprehensive information about asthma death. On World Asthma Day 2014, 24 years after the publication of the first UK guideline, the NRAD report, 'Why asthma still kills',[5] stated asthma care was poor in most cases investigated and concluded that the vast majority of asthma deaths in the UK remain potentially preventable.

In all age groups, NRAD identified errors in primary and secondary care: in making the diagnosis of asthma; in the identification of risk factors (leading to missed opportunities for optimising asthma control); and failure to provide an acceptable quality of chronic and acute asthma care. For example, 10% of those who died from asthma had been discharged from hospital within the month prior to their death and 20% had attended emergency departments in the year before dying. There was sparse evidence that these individuals were followed up properly, despite being treated for severe acute attacks.

NRAD confirmed previous research findings that many patients who died from asthma were receiving treatment for mild or moderate asthma. This exposes the innate (and rather obvious) fallacy of attempting to stratify risk in this highly variable condition simply by the number and type of asthma drugs prescribed, turning on its head the dangerous myth that a patient who needs few drugs is probably at low risk.

Comprehensive assessment by NRAD of drug use in the year prior to death showed a scarcely believable over-prescription of reliever inhalers—six people who died had been prescribed more than 50 reliever inhalers in the year prior to their death. In an era of electronic prescribing in primary care, you might well ask how on earth could this happen. NRAD was a revealing experience—if at times deeply disturbing—for the many clinicians involved in the reading and detailed assessment of individual case records of children and adults who had died. NRAD found substantial underuse of preventer inhalers, as well as the use of long acting beta-agonists as sole therapy in some patients. A clear and simple message from NRAD is that use of more than one reliever inhaler per month indicates possible poor asthma control and a need for urgent review.

NRAD also confirmed what anecdotally has been known for some time—a shocking deficit in asthma reviews and in provision of education (for patients and healthcare professionals). Less than a quarter of people who died had evidence of a personal asthma action plan (PAAP) and almost a half had no asthma review in the past 12 months. Furthermore, 46% of primary care doctors who had cared for those who had died reported that asthma reviews had been undertaken by nurses with no recognised training in asthma care.

Clearly, despite much effort and high quality asthma guidelines, NRAD has shown that the overall delivery of care is not anything like as good as it should be—perhaps explaining why the UK lags behind many other developed countries. What then are the lessons for the future? And what use should we make of NRAD in planning services for people with asthma?

While NRAD focused on asthma deaths, its findings (taken with previous evidence on variation in healthcare provision and high levels of healthcare utilisation for uncontrolled asthma) strongly suggest a different, more holistic approach is needed. NRAD is a call for action to clinicians, patients and those designing services. The traditional model of care is failing and there is a need for a different, more effective and integrated approach to asthma care delivery.

## FIVE SIMPLE MEASURES TO BE INTRODUCED WITHIN 2 YEARS ACROSS THE UK THAT COULD MAKE A BIG DIFFERENCE

### Use of informatics

Computerised general practice medical records linked to electronic prescribing are now almost universal in the National Health Service (NHS). Software providers should be commissioned to provide high risk alerts, both for patients prescribed excessive short-acting beta-agonists (SABAs) and insufficient inhaled corticosteroids (ICS) as well as those with evidence of other features of future risk of attacks, for example, as described in the 2014 evidence-based Global Initiative for Asthma strategy document.[6] Risk algorithms linked to decision support software for identifying patients with high reliever/low preventer use who have been admitted to hospital or attended an emergency department or GP for a flare-up, will reduce asthma death.

### The development of new models of care

NRAD has shown that the care of many people who have died fell into a void between hospital and general practice. New models of care across the primary/secondary care interface are needed as a matter of urgency. This should link to both the RCP's Future Hospital[7] work and the NHS Forward View.[8] The development and training of respiratory specialists in integrated care—focusing on leadership of a network based out of hospital to keep people with asthma (and other lung disorders) well and out of hospital—is central. The focus should be on ambulatory care, guided self-management utilising information technology (IT), and a more proactive approach to risk factors,

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including smoking cessation and mental health. This approach should include clear lines of responsibility, with protocols for care pathways guiding diagnosis and management, and encouraging the seeking of specialist advice where asthma is poorly controlled. For example, NRAD recommended that any patient requiring two or more courses of oral corticosteroids should be referred to an asthma expert (either in primary or secondary care), which should lead to improved control and a reduction in future attacks.

### More specialist involvement

NRAD found that almost half of asthma reviews had been undertaken by nurses without formal training. It is unsatisfactory to simply transfer care from hospital to primary care without resources to support a more specialist approach in the community. General practitioners are generalists, dealing with hundreds of different medical conditions (compared with specialists caring for 10–20 disease entities). Therefore, approaches to the provision of specialist-level delivery of care need to be investigated, such as ongoing training of interested GPs and specialist nurses, and developing asthma outreach services staffed by specialist multidisciplinary teams.

### Personal asthma action plans

PAAPs result in a better understanding of the disease by patients, and a reduction in attacks and healthcare utilisation.[8] The vast majority (77%) of patients in NRAD had no evidence of provision of a PAAP; this may be one of the explanations why 45% did not call for or get medical assistance in their final fatal asthma attack. In essence, a PAAP provides a patient with a rationale for taking regular preventer medication, recognising poor asthma control and danger signs, and a clear idea of when and who to call for help.

### National asthma audit

Medical audit provides a means of assessing care against acknowledged quality standards. NRAD has recommended a national audit which to date has not been implemented. Simple, easily obtainable, actionable outcomes reflecting current guidelines[9] could include practice information about annualised numbers of reliever and preventer prescriptions, provision of PAAPs, and reviews focusing on optimising asthma control, both annually and *also* after *every* asthma admission. With production of current, meaningful outcomes, allowing clear comparisons across healthcare providers, we see a means to end inexplicable levels of variation in care reported in the National Atlas of Variation in Healthcare for Respiratory Disease.[4]

It was shameful that in NRAD 193 primary care physicians and 59 hospitals refused to respond or sent insufficient information to be considered by the panels. This lack of engagement increased the workload of the NRAD team, and reduced the completeness of the report in that there were a considerable amount of missing data. The 'Good Medical Practice' booklet of the UK regulatory body, the General Medical Council, states that doctors have a professional obligation to participate in confidential enquiry. We believe that future enquiries should incorporate within their procedure a mandate for referring non-participants to their professional regulators.

Although NRAD considered people who had died from asthma, its findings have shone a powerful spotlight on current standards of asthma management across the UK. Are we content to do little or nothing and for our successors to read a similar report in the years to come? Perhaps the words of Edmund Burke apply: "All that is necessary for the triumph of evil is that good men do nothing".

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