

Institution: The University of Edinburgh

Unit of Assessment: 1

Title of case study: N: Detailed epidemiological studies of people with allergy have triggered policy developments and catalysed service innovations to enhance care

## **1. Summary of the impact** (indicative maximum 100 words)

**Impact:** Health and welfare, policy and services. By quantifying the high lifetime prevalence of allergy, high costs and sub-optimal NHS care, UoE researchers catalysed international policy change and UK service developments.

**Significance:** Investment in expanded allergy services and improved standards of care, resulting in a significant drop in global allergy-related mortality rates.

**Beneficiaries:** People with allergies; GPs and emergency care clinicians; policymakers and professional bodies.

Attribution: The work was led by Sheikh (UoE) with collaborators for national surveys.

**Reach:** International. 1 in 3 people in the UK have an allergy; World Allergy Organization anaphylaxis guidelines are used in 89 countries.

# **2. Underpinning research** (indicative maximum 500 words)

Epidemiological research undertaken by UoE researchers Professor Aziz Sheikh (Professor of Primary Care Research & Development, 1993–present), Dr Colin Simpson (Reader, 2009–present), Dr Mark Levy (Senior Lecturer, 2004–present) and Dr Chantelle Anandan (Post-Doctoral Fellow, 2005–present) demonstrated that the UK now has the highest prevalence of allergic disorders in the world, with 1 in 3 of the population developing one or more allergic disorder at some point in their lives [3.1]. Their subsequent retrospective General Practice Research Database-derived national birth cohort study of >40,000 children found that 1 in 2 children developed an allergic disorder within the first 18 years of life. This alerted policymakers to the fact that the overall population prevalence is likely to climb much higher in the decades ahead [3.3].

Importantly, this research, for the first time, reliably quantified healthcare utilisation and healthcare costs resulting from allergic disorders in the UK (i.e., 6% of all GP consultations; 70,000 hospital admissions/year; and 11% of all community prescribing (>£1B/year) [3.2, 3.3]. The research also identified major shortcomings in allergy care provision, highlighting the need to focus particular attention on the needs of: the 15% of children with multiple allergic disorders [3.4]; ethnic minorities [3.3]; the ~40,000 people in the UK with a history of anaphylaxis; and those with a history of other systemic, potentially life-threatening allergies [3.4]. Moreover, >80% of GPs judged NHS care to be of poor quality for the ~20 million people in the UK with allergy problems [3.5].

Subsequent descriptive, analytical and qualitative research by Sheikh, Dr Hilary Pinnock (Reader, UoE, 2004–present) and Dr Allison Worth (Senior Research Fellow, 2006–present) with patients, their families and health professionals has sought to understand the impact of living with severe allergic problems [3.6] and has been used to inform educational, policy and service developments led by Sheikh, Levy, and Professor Jürgen Schwarze (Edward Clark Chair of Child Life and Health, UoE, 2007–present).

#### **3. References to the research** (indicative maximum of six references)

3.1 Gupta R, Sheikh A, Strachan D, Anderson H. Burden of allergic disease in the UK: secondary analyses of national databases. Clin Exp Allergy. 2004;34:520–6. DOI: 10.1111/j.1365-2222.2004.1935.x.



- 3.2 Punekar Y, Sheikh A. Establishing the incidence and prevalence of clinician-diagnosed allergic conditions in children and adolescents using routinely collected data from general practices. Clin Exp Allergy. 2009;39:1209–16. DOI: 10.1111/j.1365-2222.2009.03248.x.
- 3.3 Netuveli G, Hurwitz B, Levy M,...Sheikh A. Ethnic variations in UK asthma frequency, morbidity, and health-service use: a systematic review and meta-analysis. Lancet. 2005;365:312–17. DOI: 10.1016/S0140-6736(05)17785-X.
- 3.4 Rankin K, Sheikh A. Serious shortcomings in the management of children with anaphylaxis in Scottish schools. PLoS Med. 2006;3:e326. DOI: 10.1371/journal.pmed.0030326.
- 3.5 Levy M, Price D, Zheng X, Simpson C, Hannaford P, Sheikh A. Inadequacies in UK primary care allergy services: national survey of current provisions and perceptions of need. Clin Exp Allergy. 2004;34:518–9. DOI: 10.1111/j.1365-2222.2004.1945.x.
- 3.6 Walker S, Khan-Wasti S, Fletcher M, Cullinan P, Harris J, Sheikh A. Seasonal allergic rhinitis is associated with a detrimental effect on examination performance in United Kingdom teenagers: case-control study. J Allergy Clin Immunol. 2007;120:381–7. DOI: 10.1016/j.jaci.2007.03.034.

# **4. Details of the impact** (indicative maximum 750 words)

The work was the first to alert UK governments, policymakers and professional bodies to the scale of the burden of poorly treated allergic disease and led to a range of policy and service initiatives to enhance allergy care provision.

## Impact on public policy

Since commencing this research in 2003, Sheikh and co-workers have consistently reported their findings to professional bodies and UK government. Sheikh led the national epidemiological research that informed the Scottish Medical and Scientific Advisory Committee's Review Working Group on *Allergy Services in Scotland* (2009) [5.1] and contributed to the Royal College of Physicians and Royal College of Pathologists report *Allergy Services: Still not Meeting the Unmet Need* (2010) [5.2].

Sheikh and colleagues have also provided expert clinical, methodological and leadership input in relation to national and international guidelines, for example:

- Resuscitation Council (UK) *Guidelines on Emergency Treatment of Anaphylactic Reactions* (2008) [5.3] (Sheikh was a co-author and is co-chair for the 2013 revised guidelines).
- World Allergy Organization Guidelines for the Assessment and Management of Anaphylaxis (2013) [5.4], which are used in 89 countries (Sheikh was the sole UK and one of only three European co-authors).
- World Allergy Organization *White Book on Allergy* (2011 and 2012) [5.5], which provides international gold standard recommendations for allergy care (Sheikh was a co-author).
- European Academy of Allergy and Clinical Immunology's European Declaration on Immunotherapy [5.6] (2012) (Sheikh was a co-author) and Guidelines on Anaphylaxis (2013) (Sheikh has been a member of the Guideline Executive, was the Methodology Lead and is senior author on these Europe-wide clinical guidelines).

Sheikh's involvement has harmonised the national, European and international anaphylaxis guidelines to ensure that evidence-based and consistent messages are being communicated to front-line clinicians worldwide. Key amongst these is ensuring that professionals understand that adrenaline is the first-line treatment; this has translated into more provision of potentially life-saving adrenaline auto-injectors to patients/carers.

The UoE team is closely involved with UK charities: The Anaphylaxis Campaign (Levy is Scientific Chair, Schwarze and Sheikh are members of the Scientific Committee), Allergy UK (Sheikh has provided advice on strategic direction) and Asthma UK (Schwarze is a Trustee). This involvement has broadened the focus of these charities to encompass community-based allergy care, which in turn has enhanced their capacity to fundraise. For example, Allergy UK is running a £1M appeal to



fund community-based allergy nurses across the UK (the first appointee, in Autumn 2013, will be based in Edinburgh). In 2013, Asthma UK awarded funding for the £2M community-focused Centre for Applied Asthma Research to UoE.

### Impact on practitioners and services

The policy impacts have led to many UK governmental and professional service developments. Sheikh co-authored the Department of Health-commissioned Royal College of Paediatrics and Child Health anaphylaxis care pathway for children with allergies (2011) [5.7]. Sheikh was the Royal College of General Practitioners joint inaugural Clinical Champion for Allergy (2010–2012), which led to the College designating allergy a clinical priority, and is now their Clinical Expert. The UoE team was also instrumental in the establishment of a new Managed Clinical Network in 2012: The Children and Young People's Allergy Network Scotland (CYANS; chaired by Schwarze, with Sheikh and Worth on the Steering Group and leading the National Anaphylaxis Database), which has involved over 450 healthcare professionals across Scotland [5.8]. For the National Review of Asthma Deaths (2012–13) [5.9], Levy is the Clinical Lead and Sheikh is a member of the External Expert Reviewer Group.

The UoE team has also been instrumental in driving service improvements through professional training through, for example, the BMJ Masterclass on respiratory/allergic diseases delivered by Sheikh, Pinnock and Levy. This has been given 2–4 times/year since 2008, attracting ~3000 participants from across the UK. Clinician awareness of anaphylaxis is now very high: in a 2012 survey of 3537 US paramedics, 98.9% correctly identified a case of classic anaphylaxis.

## Impact on health and welfare

Increased awareness of allergy and anaphylaxis among clinicians and patients/members of the public and harmonised evidence-based guidelines have contributed to a decline in allergy-related deaths worldwide. Dramatic decreases have been reported in Ontario, Canada: there were 31 food-related anaphylaxis deaths from 1986 to 2000 but only 6 from 2004 to 2011 [5.10]. In the UK, Sheikh and Levy are involved with re-establishing anaphylaxis and asthma fatality registries, which will enable accurate data-gathering for the future.

## Impact on society and public engagement

Sheikh has made numerous appearances in the mainstream media (e.g., Fox News, Radio 4, Telegraph, The Herald and Daily Mail) and social media discussing the changing epidemiology, risk factors, new treatments and public health implications of allergy. This has contributed to a public shift away from ineffective complementary and alternative treatments, towards greater involvement with academics (UoE has a 50-strong allergy/respiratory patient and public involvement group), charities and service planners/providers (e.g., CYANS and Care Commissioning Groups) to ensure improved, more equitable provision of evidence-based allergy care.

#### 5. Sources to corroborate the impact (indicative maximum of 10 references)

- 5.1 Scottish Medical and Scientific Advisory Committee's Review Working Group on Allergy Services in Scotland (SMASAC) report 2009. <a href="https://www.scotland.gov.uk/Publications/2009/06/17135245/0">www.scotland.gov.uk/Publications/2009/06/17135245/0</a>.
- 5.2 Royal College of Physicians and Royal College of Pathologists (2010). Allergy services: still not meeting the unmet need. <a href="http://www.rcplondon.ac.uk/sites/default/files/documents/allergy-services-still-not-meeting-the-unmet-need.pdf">http://www.rcplondon.ac.uk/sites/default/files/documents/allergy-services-still-not-meeting-the-unmet-need.pdf</a>.
- 5.3 Resuscitation Council (UK). Emergency Treatment of Anaphylactic Reactions. London: Resuscitation Council (UK), 2008. [Available on request.]
- 5.4 Simons F, Ardusso L, Dimov V,...Sheikh A, et al. World Allergy Organization Anaphylaxis Guidelines: 2013 Update of the Evidence Base. Int Arch Allergy Immunol. 2013;162:193–204. DOI: 10.1159/000354543.
- 5.5 World Allergy Organization White Book on Allergy. 2011. http://www.worldallergy.org/definingthespecialty/white book.php.

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- 5.6 Calderon M, Demoly P, Gerth van Wijk R,...Sheikh A, et al. EAACI: A European Declaration on Immunotherapy. Designing the future of allergen specific immunotherapy. Clin Transl Allergy. 2012;2:20. DOI: 10.1186/2045-7022-2-20.
- 5.7 Royal College of Paediatrics and Child Health care pathway: <a href="www.rcpch.ac.uk/child-health/research-projects/care-pathways-children-allergies/anaphylaxis/care-pathway-anaphylaxis">www.rcpch.ac.uk/child-health/research-projects/care-pathways-children-allergies/anaphylaxis/care-pathway-anaphylaxis</a> and Clark A, Lloyd K, Sheikh A, et al. The RCPCH care pathway for children at risk of anaphylaxis: an evidence and consensus based national approach to caring for children with life-threatening allergies. Arch Dis Child. 2011;96 (Suppl 2):i6–9. DOI: 10.1136/adc.2011.212662.
- 5.8 The Children and Young People's Allergy Network Scotland (CYANS). http://www.cyans.org.uk/.
- 5.9 National Review of Asthma Deaths. <a href="http://www.rcplondon.ac.uk/projects/national-review-asthma-deaths">http://www.rcplondon.ac.uk/projects/national-review-asthma-deaths</a>.
- 5.10 American Academy of Allergy, Asthma & Immunology (AAAAI) 2013 Annual Meeting: Abstract 511. Presented February 24, 2013. Discussed on Medscape website, March 7<sup>th</sup> 2013: Anaphylaxis Death Rate Down, but Epinephrine Use Poor. <a href="http://www.medscape.com/viewarticle/780414">http://www.medscape.com/viewarticle/780414</a> [Free login required. Document available on