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Challenges of harmonising data from UK national health surveys: a case study of attempts to estimate the UK prevalence of asthma

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Introduction

The United Kingdom (UK) ranks among the highest in the world in prevalence, healthcare utilisation and mortality from asthma.[1–3] Asthma therefore represents a major concern for policymakers.[5–7] There is, however, no comprehensive picture of the numbers of people with asthma or the associated morbidity and costs in the UK. This may reflect the fact that previous efforts have drawn on a limited number of datasets and have focused predominantly on a particular age group and/or UK nation.[4,7–13] We were funded by Asthma UK to investigate the epidemiology, healthcare utilisation and costs of asthma care for the UK as a whole and its member nations, i.e. England, Northern Ireland, Scotland and Wales. We interrogated serial, population-based national health surveys and routine health data in order to estimate the prevalence of asthma. Similar repeat surveys have proven useful in estimating the burden of asthma across different world regions.[14–19] Here, we describe the challenges we encountered in synthesising and harmonising data from these surveys in order to derive UK-wide estimates on the most basic of these outcomes, namely the prevalence of asthma, which is the proportion of individuals in a population who have asthma at a specified point in time (point prevalence) or during a specified time period (period prevalence) or at any time during a year (annual prevalence) or at any time during their life course (lifetime prevalence).[20] It should be noted that a more objective diagnosis of asthma is based on careful clinician assessment, following the guidelines provided by the National Institute for Health and Care Excellence (NICE). In this essay, we propose possible solutions to help ensure that the significant resources invested in these national surveys generate comparable data on asthma and possibly other disease areas.

National health surveys

Each UK nation undertakes serial population-based cross-sectional surveys of randomly selected samples of people, broadly representative of the population living in private households. These surveys collect information on health and disease, utilisation of healthcare and social services and factors that affect health. The data are extensively used by policymakers and service planners for organising healthcare and to an extent social care services; they also serve as

important data sources for researchers in investigating population health and its determinants. The surveys are implemented by respective national social and health service institutions and the survey instruments and data are archived by the UK Data Archive (http://www.data-archive.ac.uk/). Our study period was 2001–2012.

Health Survey for England

The Health Survey for England began in 1991 and is undertaken annually. It includes core sets of questions and anthropometric and biological measurements on various disease conditions; each year's survey also focuses on a particular disease condition or population group. Participants are selected using a stratified random probability sample of households. Since 2001, all age groups, from infants aged six weeks and older, have been sampled. The respiratory module of the survey has varied in content but usually covers symptoms, diagnoses and treatment for asthma and symptoms of chronic obstructive pulmonary disease (COPD). Over the current project period, the respiratory module was included in the 2001, 2002 and 2010 surveys.

Northern Ireland Health and Social Wellbeing Survey and Northern Ireland Health Survey

The Northern Ireland Health and Social Wellbeing Survey was undertaken in 1997, 2001 and 2005/2006 but was replaced by the Northern Ireland Health Survey in 2010/2011 which now runs annually, both surveys having similar designs and topics covered. Respondents were randomly selected adults, ≥16 years; parents or guardians responded on behalf of any child in the household aged 2–15 years. We used the 2001 and 2005/2006 Northern Ireland Health and Social Wellbeing Survey surveys and the 2010/2011 Northern Ireland Health Survey.

Scottish Health Survey

The Scottish Health Survey began in 1995; it was repeated in 1998, 2003 and 2008, and then moved to a continuous (rolling) design with annual reports published since 2008. A representative sample of households and participants across Scotland are selected using two-stage cluster sampling. The survey included a personal interview undertaken by trained interviewers and a nurse visit in a sample of the participants that included anthropometric and biological measurements. For the current project, asthma-related questions were included in the 2003, 2008 and 2010 surveys.

Welsh Health Survey

The current Welsh Health Survey began in 2003, replacing two previous surveys: the Welsh Health Survey conducted in 1995 and 1998 and the Health in Wales Survey conducted five times between 1985 and 1996. The Welsh Health Survey has been undertaken annually and constitutes an unclustered sample of adults and children selected from strata of local authorities. The content of the Welsh Health Survey has been largely the same since it was established with the inclusion of questions on the health of children in 2007. For the current project, asthma-related questions were included in the 2003, 2007, 2008, 2010 and 2011 surveys.

Asthma questions across national health surveys

Identical questions were posed in the English and Scottish surveys about lifetime and recent wheezing symptoms, but no wheezing symptom-related question was posed in the surveys from Wales and Northern Ireland (Table 1). In the English, Scottish and Northern Ireland surveys, the question about clinician-diagnosed asthma was similar, but was not posed in the Welsh survey. An additional question on asthma symptoms during the past 12 months was posed in the English survey, while in Northern Ireland the question was on asthma attacks in the past 12 months. The English and Northern Ireland surveys posed similar questions on asthma medication use or treatment for asthma, i.e. whether the respondent had used any asthma medication during the past 12 months. In the Scottish survey, the question was whether the respondent had received treatment or advice for asthma from a list of health professionals in the past 12 months. In the Welsh survey, the sole question was whether the respondent was currently being treated for asthma.

Defining asthma and harmonising definitions across national surveys

Utilising the asthma questions across the surveys, we aimed to define self-reported: (1) lifetime and current symptoms suggestive of asthma; (2) lifetime and current clinician-diagnosed asthma; and (3) current treated clinician-diagnosed asthma. Our goal was to harmonise these asthma definitions across national

Table 1. Asthma questions posed in respective national surveys in the UK.

Nation, survey and survey years studied	Different asthma definitions and applicable survey questions				
	Lifetime symptomatic asthma	Lifetime clinician-diagnosed asthma	Current symptomatic asthma	Current clinician-diagnosed asthma	Current treated clinician-diagnosed asthma
England, Health Survey for England 2001, 2002, 2004, 2010	Have you ever had wheezing or whistling in the chest at any time, either now or in the past?	Did a doctor or nurse ever tell you that you had asthma?	Have you had wheezing or whistling in the chest in the last 12 months?	Did a doctor or nurse ever tell you that you had asthma? **AND/OR** Have you had wheezing or whistling in the chest in the last 12 months?	Did a doctor or nurse ever tell you that you had asthma? **AND** Over the last 12 months, have you used an inhaler, puffer or nebuliser prescribed by a doctor to treat your asthma, wheezing or whistling, or difficulty in breathing?
Northern Ireland, Northern Ireland Health and Social Wellbeing Survey and the Northern Ireland Health Survey 2001, 2005/2006, 2010/2011		Have you ever been told by a doctor that you had any of the conditions on this card? (asthma)		Have you ever been told by a doctor that you had any of the conditions on this card? (asthma) **AND** (Have you had an asthma attack during the past 12 months? **OR** Do you currently suffer from any of the following conditions? (asthma))	Have you ever been told by a doctor that you had any of the conditions on this card? (asthma) **AND** (Have you had an asthma attack during the past 12 months? **OR** (Do you currently suffer from any of the following conditions? (asthma)) **AND** In the past 12 months, have you taken medication for asthma such as inhalers, nebulisers, pills, liquids or injections?)
Scotland, Scottish Health Survey 2003, 2008, 2010	Have you ever had wheezing or whistling in the chest at any time, either now or in the past?	Did a doctor ever tell you that you had asthma?	Have you ever had wheezing or whistling in the chest in the last 12 months?	Did a doctor ever tell you that you had asthma? **AND** Have you ever had wheezing or whistling in the chest in the last 12 months?	Did a doctor ever tell you that you had asthma? **AND** Have you received any treatment or advice for your (asthma/wheezing or whistling) from any of the people on this card last 12 months?
Wales, Welsh Health Survey 2003, 2007, 2008, 2010, 2011					Are you currently being treated for any of these? (asthma)

surveys in order to derive both nation-specific and UK-wide estimates of asthma prevalence. However, formulating working definitions of lifetime and current symptoms suggestive of asthma was only possible within the English and Scottish surveys, while formulating working definitions of lifetime and current clinician-diagnosed asthma was possible within the English, Northern Ireland and Scottish surveys (Table 1).

A working definition of 'current treated clinician-diagnosed asthma' was derived using questions on both treatment and diagnosis from the English, Northern Ireland and Scottish surveys and by assuming diagnosis implicit in the sole Welsh question, 'Are you currently being treated for asthma?' While it is unlikely that Welsh respondents who reported being currently treated for asthma were never given a diagnosis of asthma, this still leads to a lack of uniformity across surveys. This might be important as some asthma medications are used for other conditions, and it is therefore possible that the prevalence of treated asthma in Wales has been over-estimated. Apart from the definition of current treated asthma, it was impossible to harmonise other working definitions of asthma across national surveys because the questions related to these definitions were not asked across all surveys.

Comparing estimates of asthma prevalence across national surveys

To compare the estimates of asthma prevalence derived from the above definitions between each nation, we calculated sex-specific prevalence estimates in adults (≥16 years) where data were available based on the 2010/2011 national surveys (the latest survey in all nations during the project period, except for Wales). The estimates were directly age-standardised using the 2013 European Standard Population (Table 2). The prevalence of all outcomes was highest in England (for both sexes) compared to other countries, except for the prevalence of current treated clinician-diagnosed asthma which was highest in Wales (Table 2). While there were moderate differences between nations in the prevalence of lifetime clinician-diagnosed asthma, the relative differences in current clinician-diagnosed asthma (49–142% in men) and current treated clinician-diagnosed asthma (up to 70% in men) were larger. It is unclear whether these are real differences or a result of the ways these questions have been framed in each nation. For instance, the question on clinician-diagnosed asthma referred to a 'doctor or nurse' in England, while it referred only to a 'doctor' in Scotland and Northern Ireland. Furthermore, the questions combined to define clinician-diagnosed asthma focused on wheezing symptoms in England and Scotland but asked about asthma attacks in Northern Ireland. It is unclear how the question on asthma attacks might have been interpreted by participants as this was not asked in the other surveys.

Concluding remarks and suggestions for future work

Serial health surveys are useful sources for estimating the prevalence of self-reported symptoms of a number of health conditions. In the field of asthma research, the International Study of Asthma and Allergy in Childhood (ISAAC) is an important example of a serial research study, which has generated comparable longitudinal data on the epidemiology and risk factors for asthma and allergy across different world regions.[15] However, as a result of the different ways in which questions on asthma have been asked across national surveys, our attempt to interrogate UK surveys has shown that deriving comparable prevalence estimates across UK nations is challenging. These differences limit the possibility of harmonisation and formulation of common working definitions of asthma across the four nations and limited our goal of deriving reliable UK-wide and nation-specific estimates of reported prevalence of asthma symptoms, clinician-diagnosed asthma and clinician-diagnosed current asthma requiring treatment.

Assessments of other disease conditions was beyond our remit, but we believe that a fundamental step in mitigating similar problems is that there should be greater dialogue and cooperation between institutions responsible for organising the surveys across the UK nations. Such closer working ties will ensure that consideration is given to ensuring core questions are posed across national surveys. This will then allow harmonisation of the definitions of asthma across nations and will facilitate derivation of a UK-wide and comparable national-specific estimates of the prevalence of asthma (and possibly other long-term conditions). In addition, such cooperation could facilitate the planning and conduct of the surveys during the same year and season across the four UK nations, where possible, which will ensure better comparison of the annual and seasonal variations in the prevalence of asthma across the UK. Similarly, as we capitalise on the potentials of the various routine data sets in the UK in addressing key population health questions, increasing efforts are needed to ensure that outcomes are consistently defined across nations and coding systems are continuously standardised.

Table 2. Age-standardised[a] prevalence of asthma in adults (≥16 years) per 1000 population based on the different asthma definitions given in Table 1: estimates are based on the 2010/2011 survey used in the project from each UK nation.

Nation and survey year	*N*[b]	Lifetime symptomatic asthma Prevalence (95% CI)[c] Numerator[d]	Lifetime clinician-diagnosed asthma Prevalence (95% CI)[c] Numerator[d]	Current symptomatic asthma Prevalence (95% CI)[c] Numerator[d]	Current clinician-diagnosed asthma Prevalence (95% CI)[c] Numerator[d]	Current treated clinician-diagnosed asthma Prevalence (95% CI)[c] Numerator[d]
Men						
England, 2010	3702	332 (315–350) 1377	155 (143–167) 670	189 (175–202) 768	97 (87–107) 409	83 (74–92) 345
Northern Ireland, 2010/2011	1684		114 (97–131) 180		40 (29–50) 58	
Scotland, 2010	1014	248 (218–278) 279	132 (110–154) 151	149 (125–171) 166	65 (50–81) 74	54 (40–68) 61
Wales, 2010	7041					92 (85–100) 669
Women						
England, 2010	4718	311 (294–328) 2718	169 (157–181) 736	181 (168–194) 779	117 (107–127) 506	104 (94–113) 447
Northern Ireland, 2010/2011	2401		122 (108–137) 278		44 (35–53) 97	5
Scotland, 2010	1374	254 (226–282) 317	144 (110–154) 194	156 (134–178) 360	76 (61–92) 95	73 (58–88) 90
Wales, 2010	8118					122 (114–130) 946

Empty cells mean no data available; although questions on treated asthma were asked in the surveys from Northern Ireland, data were lacking for these variables.
[a]Standardisation was undertaken using the European Standard Population 2013 revision.
[b]Unweighted bases.
[c]All confidence intervals undertaken using the Poisson Approximation.
[d]Weighted number of cases.

Box 1. Core set of asthma questions in defining prevalence measures for self-report asthma from UK national surveys.

Core set of questions to include in future surveys

A. Have you ever had wheezing or whistling in the chest at any time, either now or in the past?
B. Have you had this wheezing or whistling in the chest in the last 12 months?
C. Did a doctor or nurse ever tell you that you had asthma at any time, either now or in the past?
D. Have you had any symptoms of asthma in the last 12 months?
E. Have you received any treatment for your asthma/wheezing/whistling in the chest in the last 12 months?

Defining different asthma prevalence measures based on above questions

Prevalence of lifetime symptoms suggestive of asthma: *(question **A**)*
Prevalence of current symptoms suggestive of asthma: *(combination of questions **A** and **B**)*
Prevalence of lifetime clinician-diagnosed asthma: *(question **C**)*
Prevalence of current clinician-diagnosed asthma: *(combination of either questions **B** and **C** or **C** and **D**)*
Prevalence of current treated clinician-diagnosed asthma: *(combination of either questions **B** and **C** and **E** or **C** and **D** and **E**)*

Drawing on our experience of using these surveys, we have identified a core set of asthma questions for defining different measures of asthma prevalence (Box 1). We suggest that these should be considered in future national health surveys. While there may be a need to retain some of the original questions that have been posed in each national survey in order to analyse trends, we suggest that these core set of questions be included in future surveys. We believe this will enable direct comparison across nations and derivation of UK-wide estimates. These core questions are comparable to the questions from the World Health Survey,[17,18] ISAAC[15,19] and the European Community Respiratory Health Survey (ECHRS),[20] but some slight differences remain, particularly the inclusion of a 'nurse' in Question C; this is important as nurses may diagnose asthma in the UK. Question D is an additional question not appearing in the World Health Survey, ISAAC and ECHRS, but we believe it is a good complement to Questions A and B when combined with Question C in deriving current clinician-diagnosed asthma. ISAAC does not have a question on physician-diagnosed asthma and medication or treatment explicitly, but the World Health Survey and ECHRS do. Finally, similar analyses need to be considered in relation to the questions in other disease areas to ascertain whether failure to harmonise questions is widespread.

Declarations

Competing interests: None declared

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Guarantor: AS

Contributorship: AS conceived the idea for this paper. It was drafted by BN and was then revised after several rounds of critical comments by AS and additional feedback from all authors.

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