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


Published in:
Journal of the Royal Society of Medicine

Document Version:
Early version, also known as pre-print

Queen's University Belfast - Research Portal:
Link to publication record in Queen's University Belfast Research Portal

Publisher rights
© 2015 The Authors

General rights
Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.
Challenges of harmonising data from UK national health surveys: a case study of attempts to estimate the UK prevalence of asthma

Bright I Nwaru, Gwyneth Davies, David P Strachan, Michael Shields, Aziz Sheikh, on behalf of the Burden and True Cost of Asthma in the UK Research Team

Asthma UK Centre for Applied Research, Centre for Population Health Sciences, The University of Edinburgh, Edinburgh, UK
Bright I Nwaru research fellow
Asthma & Allergy Group, Institute of Life Science, College of Medicine, Swansea University, Swansea, UK
Gwyneth Davies senior lecturer
Population Health Research Institute, St George's University of London, London, UK
David Strachan professor
Centre for Infection and Immunity, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, Belfast, UK
Michael Shields professor
Asthma UK Centre for Applied Research, Centre for Population Health Sciences, The University of Edinburgh, Edinburgh, UK
Aziz Sheikh professor

Correspondence to:
Aziz Sheikh, MD
Allergy & Respiratory Research Group,
Centre or Population Health Sciences,
The University of Edinburgh,
Teviot Place,
Edinburgh EH8 9AG, UK
aziz.sheikh@ed.ac.uk

Key words
asthma, health surveys, policymakers, prevalence, United Kingdom

Word count: 1997
Considerable resources are invested in population-based health surveys in order to provide estimates of disease prevalence and severity, but our recent attempt to estimate the UK prevalence of asthma from these health surveys identified major differences in the questions used by UK nations thus making it very challenging to generate comprehensive UK-wide estimates from these national datasets.

The United Kingdom (UK) ranks among the highest in the world in the prevalence, healthcare utilisation, and mortality from asthma.\textsuperscript{1-4} Asthma therefore rightly represents a major concern for policymakers.\textsuperscript{5-7} There is however no comprehensive overall picture of the numbers of people with asthma or indeed the associated morbidity and costs, this reflecting the fact that previous efforts have drawn on isolated or limited number of datasets, which have focused predominantly on a particular age group and/or UK nation.\textsuperscript{4,8-14} We were commissioned 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. Fundamental to this work was our plan to interrogate 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 appreciating the burden of asthma across different world regions.\textsuperscript{15-20} Here we describe the challenges we encountered in interrogating and harmonising data from these serial population-based health surveys in order to derive UK-wide estimates on the most basic of these outcomes, namely the prevalence of asthma. We conclude by proposing possible solutions that will 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 a randomly selected sample of people from the general population, which collect information on health and diseases, utilisation of healthcare and social services, and on factors that affect health. The data from these surveys are extensively used by policymakers and service planners for organising healthcare and to an extent social care services; these have also served as important sources of data for researchers in investigating population health and its determinants. The surveys are implemented by respective national social and health service institutions and the data are archived by the UK Data Archive (http://www.data-archive.ac.uk/). We utilised the surveys described below for the period 2001-2012:

\textbf{Health Survey for England (HSE)}
The HSE began in 1991 and is carried out annually. It includes core sets of questions and measurements on various disease conditions; each year’s survey however also focuses on a
particular disease condition or a specific population group. Participants are selected by means of a stratified random probability sample of households. Since 2001, all age groups, from infants of six weeks and older, have been sampled. The respiratory module of the survey covers symptoms, diagnoses and treatment for asthma and chronic obstructive pulmonary disease (COPD); over the current project period, the respiratory module was included in 2001, 2002, 2004, and 2010 surveys.

**Northern Ireland Health and Social Wellbeing Survey (NIHSWS) and Northern Ireland Health Survey (NIHS)**

NIHSWS was carried out in 1997, 2001, and 2005/2006, but was replaced by NIHS 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 children. We used the 2001 and 2005/2006 NIHSWS surveys and the 2010/2011 NIHS.

**Scottish Health Survey (SHeS)**

SHeS began in 1995; repeated in 1998, 2003 and 2008, and has been undertaken annually since 2008. Representative sample of households and participants across Scotland are selected using cluster sampling. Each survey involves two stages of interviews: a personal interview undertaken by trained interviewers and a nurse visit in a sample of the participants that includes an interview and anthropometric and biological measurements. For the current project, asthma-related questions were included in 2003, 2008, 2010, and 2012 surveys.

**Welsh Health Survey (WHS)**

The current WHS began in 2003; it replaced two previous serial surveys: the WHS conducted in 1995 and 1998 and the Health in Wales Survey conducted five times between 1985 and 1996. Since its, the WHS has been carried out annually and constitutes an un-clustered sample of adults and children selected from strata of local authorities. The content of the WHS has been largely the same since it was established in 2003, with the inclusion of questions on the health of children in 2007. For the current project, asthma-related questions were included in 2003, 2007, 2008, 2010, 2011, and 2012 surveys.

**Asthma questions across national surveys**

Identical questions were asked in the HSE and the SHeS about wheezing symptoms, but no wheezing symptom related question was asked 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 asked in the Welsh survey. An
additional question on asthma symptom during the past 12 months was asked in the English survey while in the Northern Ireland surveys the question was on asthma attacks in the past 12 months. The English and Northern Ireland surveys asked similar questions on use of asthma medication or treatment for asthma; i.e. on whether the respondent has used any asthma medication during the past 12 months. In the Scottish survey, the question was on whether the respondent has received treatment or advice for asthma from a list of health professionals in the past 12 months. In the Welsh survey, the question was on whether the respondent was currently being treated for asthma, and this was the only asthma question asked in the Welsh survey.

Defining asthma, harmonising definitions, and comparing estimates of asthma prevalence across national surveys

By utilising the asthma questions asked across the surveys, we aimed to define: (1) reported lifetime and current symptoms suggestive of asthma; (2) reported lifetime and current clinician-diagnosed asthma; and (3) reported current treated clinician-diagnosed asthma. Our goal was to harmonise these asthma definitions across national surveys in order to derive both national-specific and UK-wide estimates of asthma prevalence. However, as shown in Table 1, formulating working definitions of lifetime and current symptoms suggestive of asthma were only possible within the English and Scottish surveys, while formulating working definitions of lifetime and current clinician-diagnosed asthma were possible within the English, Northern Ireland, and Scottish surveys. Developing a working definition of current treated clinician-diagnosed asthma was possible within all the national surveys, but the definition used within the Welsh survey was different from that used by the other surveys as only one question (on whether the respondent is currently being treated for asthma) was asked in that survey, whereas the combination of questions in the other surveys ensured that those receiving medication or being treated for asthma also reported being diagnosed as having asthma. Although it is unlikely that those that reported being currently treated for asthma would actually have no asthma, the conditioning of the treatment part of the definition on reported clinician-diagnosed asthma ensured a uniformity of definition across surveys. This conditioning is important given that some asthma medications may be used for other conditions. Overall, 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.

To compare the estimates of asthma prevalence as derived from the above definitions between each nation, we calculated the age-standardised gender-specific prevalence estimates in adults (≥16 years) where data were available based on the 2010/2011 national
surveys (which was the latest survey in all nations during the project period, except for Wales) using the European Standard Population 2013 version as the reference population (Table 2). The prevalence of all outcomes was highest in England across gender compared to other countries, except for the prevalence of current treated clinician-diagnosed asthma which was highest in Wales (Table 2). While the differences between nations regarding lifetime clinician-diagnosed asthma appeared reasonable, the differences regarding current clinician-diagnosed asthma and current treated clinician-diagnosed asthma were large: for current physician-diagnosed asthma, up to 49% difference between England and Scotland and 142% between England and Northern Ireland in men, and up to 54% difference between England and Scotland and 166% between England and Northern Ireland in women; for current treated clinician-diagnosed asthma, up to 70% difference between Wales and Scotland in men and up to 67% difference between Wales and Scotland in women. It is thus unclear whether these are real differences or as a result of the specific 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 question combined to define clinician-diagnosed asthma focused on wheezing symptoms in England and Scotland, but asked for asthma attacks in Northern Ireland. It is unclear how intuitive a question on asthma attacks appears to participants. The question on treated clinician-diagnosed asthma in Wales was only a single question asking whether the participant is currently receiving treatment for asthma.

**Concluding remarks and suggestions for future work**

Serial health surveys are potential 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.\textsuperscript{15} However, our attempt to interrogate and work on UK surveys has shown that deriving prevalence estimates across UK nations can prove very challenging as a result of the different ways in which questions on asthma have been asked across national surveys. These differences limited the possibility of meaningful harmonisation and formulation of common working definitions of asthma across the four nations and thus precluded our overall goal of deriving reliable UK-wide and nation-specific estimates of reported prevalence of asthma symptom, clinician-diagnosed asthma, and clinician-diagnosed current asthma requiring treatment.
We do not know how widespread the above challenges are with regards to other disease conditions, but we believe that a fundamental step in mitigating these is that there should be greater dialogue cooperation between institutions responsible for organising the surveys across the UK nations. Such closer working ties will ensure that consideration is given to ensuring that the same questions are asked across national surveys, which will then allow more comparability and harmonisation of the definitions of asthma across nations and, accordingly 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 also facilitate the planning and conduct of the surveys during the same year and season across the four nations, where possible, which will ensure better comparison of the annual and seasonal variations in the prevalence of asthma across the UK.

Drawing on our ongoing experience of using these surveys, we have identified a core set of asthma questions for defining different measures of asthma prevalence (Box 1), which we suggest should be considered in future national health surveys. While there may be a need to retain the original questions that have been asked in each national survey in order to maintain historicity and time-trend analysis, we suggest that these core set of questions be integrated and included in future surveys, which we believe 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,\(^\text{17,18}\) ISSAC,\(^\text{15,19}\) and the European Community Respiratory Health Survey (ECHRS),\(^\text{20}\) 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 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 asthma diagnosis and medication or treatment, but World Health Survey and ECHRS do. Finally, similar analyses need to be considered in relation to the questions in other disease areas to ascertain how widespread an issue this failure to harmonise questions is.
Box 1 Core set of asthma questions in defining different asthma prevalence measures

<table>
<thead>
<tr>
<th>Core set of questions to include in future surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Have you ever had wheezing or whistling in the chest at any time, either now or in the past?</td>
</tr>
<tr>
<td>B. Have you had this wheezing or whistling in the chest in the last 12 months?</td>
</tr>
<tr>
<td>C. Did a doctor or nurse ever tell you that you had asthma at any time, either now or in the past?</td>
</tr>
<tr>
<td>D. Have you had any symptoms of asthma in the last 12 months?</td>
</tr>
<tr>
<td>E. Have you received any treatment for your asthma/wheezing/whistling in the last 12 months?</td>
</tr>
</tbody>
</table>

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

Key messages

- Serial population health surveys are useful data sources for generating estimates about the prevalence of asthma and many other long-term conditions
- Our attempt to harmonise asthma questions from serial national surveys across the UK in order to derive UK-wide and comparable national-specific prevalence estimates of asthma proved very challenging because of the variations in the availability and framing of relevant asthma questions across the national surveys
- We have identified a core set of asthma questions that we suggest should be used across all four nations in future surveys
- Future planning of these surveys should involve closer cooperation across the UK nations in order to allow for more comparability and harmonisation of survey questions and to ensure the respiratory modules are included in the same years; and consideration needs to be given to undertaking similar work in other disease areas.
References


ACKNOWLEDGEMENTS
We are grateful to the UK Data Service for granting us access to the national health surveys data used for this project. We would also like to thank colleagues working with us on the Asthma UK grant AUK-PG-2012-178.

FUNDING
This work was supported by Asthma UK grant AUK-PG-2012-178. Aziz Sheikh was supported by The Commonwealth Fund, a private independent foundation based in New York City. The views presented here are those of the author and not necessarily those of The Commonwealth Fund, its directors, officers, or staff.

CONFLICT OF INTEREST
We have read and understood BMJ policy on declaration of interests and declare no competing interest related to this work.

CONTRIBUTORSHIP
Aziz Sheikh conceived the idea for this paper. It was drafted by Bright Nwaru and was then revised after several rounds of critical comments by Aziz Sheikh and additional feedback from Gwyn Davies, Mike Shields and David Strachan.

LICENCE
"The Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, an exclusive licence (or non exclusive for government employees) on a worldwide basis to the BMJ Publishing Group Ltd ("BMJ"), and its Licensees to permit this article (if accepted) to be published in The BMJ's editions and any other BMJ products and to exploit all subsidiary rights, as set out in our licence."
Table 1 Asthma questions asked in respective national surveys in the UK

<table>
<thead>
<tr>
<th>Nation, Survey and survey years studied</th>
<th>Lifetime symptomatic asthma</th>
<th>Lifetime clinician-diagnosed asthma</th>
<th>Current symptomatic asthma</th>
<th>Current clinician-diagnosed asthma</th>
<th>Current treated clinician-diagnosed asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>England, Health Survey for England 2001, 2002, 2004, 2010</td>
<td>Have you ever had wheezing or whistling in the chest at any time, either now, or in the past?</td>
<td>Did a doctor or nurse ever tell you that you had asthma?</td>
<td>Have you had wheezing or whistling in the chest in the last 12 months?</td>
<td>Did a doctor or nurse ever tell you that you had asthma? <strong>AND</strong> (Have you had any symptoms of asthma in the last 12 months, or are they controlled by medication? <strong>OR</strong> Have you had wheezing or whistling in the chest in the last 12 months?)</td>
<td>Did a doctor or nurse ever tell you that you had asthma? <strong>AND</strong> 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?</td>
</tr>
<tr>
<td>Northern Ireland, Northern Ireland Health and Social Wellbeing Survey and the Northern Ireland Health Survey 2001, 2005/2006, 2010/2011</td>
<td>Have you ever been told by a doctor that you had any of the conditions on this card? (asthma)</td>
<td>Have you ever been told by a doctor that you had any of the conditions on this card? (asthma)</td>
<td>Have you ever been told by a doctor that you had any of the conditions on this card? (asthma)</td>
<td>Have you ever been told by a doctor that you had any of the conditions on this card? (asthma) <strong>AND</strong> (Have you had an asthma attack during the past 12 months? <strong>OR</strong> Do you currently suffer from any of the following conditions? (asthma)) <strong>AND</strong> In the past 12 months, have you taken medication for asthma such as inhalers, nebulizers, pills, liquids or injections?)</td>
<td>Have you ever been told by a doctor that you had any of the conditions on this card? (asthma) <strong>AND</strong> (Have you had an asthma attack during the past 12 months? <strong>OR</strong> Do you currently suffer from any of the following conditions? (asthma)) <strong>AND</strong> In the past 12 months, have you taken medication for asthma such as inhalers, nebulizers, pills, liquids or injections?)</td>
</tr>
<tr>
<td>Scotland, Scottish Health Survey 2003, 2008, 2010</td>
<td>Have you ever had wheezing or whistling in the chest at any time, either now or in the past?</td>
<td>Did a doctor ever tell you that you had asthma?</td>
<td>Have you ever had wheezing or whistling in the chest in the last 12 months?</td>
<td>Did a doctor ever tell you that you had asthma? <strong>AND</strong> Have you ever had wheezing or whistling in the chest in the last 12 months?</td>
<td>Did a doctor ever tell you that you had asthma? <strong>AND</strong> Have you received any treatment or advice for your (asthma/wheezing or whistling) from any of the people on this card last 12 months?</td>
</tr>
</tbody>
</table>
### Table 2: Age-standardised 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

<table>
<thead>
<tr>
<th>Nation and survey year</th>
<th>N²</th>
<th>Lifetime symptomatic asthma n² (Prevalence, 95% CI)³</th>
<th>Lifetime clinician-diagnosed asthma n³ (Prevalence, 95% CI)³</th>
<th>Current symptomatic asthma n⁴ (Prevalence, 95% CI)⁴</th>
<th>Current clinician-diagnosed asthma n⁴ (Prevalence, 95% CI)⁴</th>
<th>Current treated clinician-diagnosed asthma n⁵ (Prevalence, 95% CI)⁴</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MEN</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern Ireland, 2010/2011</td>
<td>1684</td>
<td>180 (114, 97-131)</td>
<td></td>
<td></td>
<td>58 (40, 29-50)</td>
<td></td>
</tr>
<tr>
<td>Scotland, 2010</td>
<td>1014</td>
<td>279 (248, 218-278)</td>
<td>151 (132, 110-154)</td>
<td>166 (149, 125-171)</td>
<td>74 (65, 50-81)</td>
<td>61 (54, 40-68)</td>
</tr>
<tr>
<td>Wales, 2010</td>
<td>7041</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>669 (92, 85-100)</td>
</tr>
<tr>
<td><strong>WOMEN</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scotland, 2010</td>
<td>1374</td>
<td>317 (254, 226-282)</td>
<td>194 (144, 110-154)</td>
<td>360 (156, 134-178)</td>
<td>95 (76, 61-92)</td>
<td>90 (73, 58-88)</td>
</tr>
<tr>
<td>Wales, 2010</td>
<td>8118</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>946 (122, 114-130)</td>
</tr>
</tbody>
</table>

¹Standardisation was undertaken using the European Standard Population 2013 revision
²Unweighted bases
³Weighted events
⁴All confidence intervals undertaken using the Poisson Approximation
**Shaded cells means no data available; although questions on treated asthma was asked in the surveys from Northern Ireland, data were lacking for these variables