Smoking questions on the Australian death notification form: adopting international best practice?

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ABSTRACT

- Australia's achievement in tobacco control has been remarkable, but relies on indirect estimates of tobacco-attributed mortality, and on using relative risks from Western countries to calculate tobacco's impact.
- To accelerate the decline in smoking, more precise measures of tobacco's relative importance among different population subgroups are required.
- We propose that more direct and accurate measures of tobacco-attributed mortality are needed, which could be achieved by adding a small set of voluntary questions about the smoking status of the deceased to a revised death notification form. Ideally, this form should also record the smoking status of the next-of-kin or family informant, as this would help establish a living control group.
- Such information will provide data on tobacco-attributed deaths with incomparable precision, allowing accurate monitoring of the current state of the smoking epidemic, and its evolution over time. This is particularly pertinent for sections of the population in which tobacco control measures have been less successful.
- A number of practical concerns have been raised, but we do not believe these are insurmountable.

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It is a great accolade for Australia's tobacco control achievements that we have been labelled "one of the darkest markets in the world" by British American Tobacco.[1] Recent reports from the Australian National Preventative Health Taskforce[2] and Scollo and Winstanley[3] are testaments to that achievement. These authors refer to the work of Begg and colleagues[4,5] which shows that smoking still causes the greatest number of disability-adjusted life-years (7.8%) lost in Australia, indicating that tobacco smoking remains the largest single cause of preventable mortality and morbidity in this country. However, indirect methods were used to make this assessment, as there are no direct, accurate estimates of this effect, nor its evolution over time. We argue that indirect methods for estimating the effect of tobacco are limited, and propose adding questions on smoking to death notification forms to provide direct estimates of tobacco-attributed mortality.

Estimating the effects of smoking

Australia was an early innovator of applying indirect techniques[6] to estimate the effects of tobacco, based on international estimates applied to local data.[7,8] Using this approach, about 15% of deaths between 1998 and 2000 were attributed to smoking (about 19 000 of the 130 000 deaths per annum).[9,10] These estimates have now been revised to 15 000 deaths per annum as a result of changes in the methods of estimation and assumptions about relative risk.[4] Among male doctors in the United Kingdom, up to two-thirds (instead of, previously, half) of continuing smokers are now killed prematurely by their habit,[11] and if these results are broadly generalisable, such estimates may need further revision. Yet, in New South Wales, there is an eightfold variation in men and a 16-fold variation in women in the risk of lung cancer, depending on their place of birth.[12] With a quarter of the Australian population born abroad, continued reliance on indirect estimates inferred from Western studies is likely to be contestable. By contrast, great efforts are made to compute direct estimates of the burden of illness due to cancers, such as those of the cervix and breast, for which established screening programs exist.[13]

Just as we obtain and rely on detailed information for other prevention programs, public policy on tobacco control ought to be based on equally accurate and direct information on the local contribution of tobacco smoking to leading causes of death (eg, vascular disease and lung cancer) and to other causes of death (eg, cancer of the liver, cervix, pancreas, bladder, oesophagus, head and neck, and kidney, together with myeloid leukaemia,[14] as well as kidney disease,[15] tuberculosis,[16-18] and ulcers[19]) known to be associated with tobacco smoking, and how these effects change over time. In absolute terms, deaths from these "other" causes of death exceed the number of deaths from lung cancer. In addition, some of these causes, such as liver cancer[20] and kidney disease,[21] are increasing in incidence, yet we have no precise idea of the contribution of tobacco smoking to their epidemiology. There is considerable debate about how to shape tobacco control programs for the part of the population that still smokes, whether current interventions will continue to work and, also, how to obtain reliable data from the increasingly marginalised and hard-to-reach segments of the Australian population among whom smoking is still common. Put simply, we are using yesterday's tools to shape today's policy on tobacco control. Without reliable information, future tobacco control policies will continue to rely on innovative yet blunt methods, and thus be compromised.

We agree with Peto and colleagues[22] who have always insisted that direct approaches are required for making accurate and locally valid estimations of deaths caused by smoking tobacco. Direct approaches typically include large prospective studies. The 45 and Up Study has just completed enrolling 250 000 residents in NSW, but data on morbidity or deaths will take over a decade to accumulate.[23] In New Zealand, questions on smoking have been ingeniously included in the national census and linked to death notifications.[24,25] Important differences in tobacco-attributed mortality were found between Maori and non-Maori populations. Furthermore, these differences in risk attributed to tobacco were shown to evolve over time[25] — the tobacco epidemic is not static.[26]

Gathering the data to enable direct estimates of mortality from smoking

Our preliminary assessment of privacy concerns in Australia suggests a census-based approach to obtaining a direct estimate of tobacco-attributed deaths is not immediately feasible. We instead

propose that the Australian state and territory registrars of Births, Deaths and Marriages add questions to the death notification forms on the smoking status of the deceased. First suggested by Peto and Doll,[26] this technique would enable much more accurate estimation of tobacco-attributable deaths for subgroups defined by geographical location, Indigenous status or place of birth. This is not possible using indirect methods. An equivalent approach has already been used (more extensively) in China, where interviews were conducted with family members (or other local informants) of one million deceased individuals, requesting standardised information on the smoking habits of the deceased and of the informant.[16,27] Impressively precise estimates of the impact of tobacco smoking can now be calculated. In South Africa, questions to establish whether deceased people and their informants were smokers were introduced in 1998 by means of adding questions to a revised death notification form.[18] Now, around one million records are available. In Hong Kong, a similar approach yielded information about the smoking habits of about 21 000 deceased individuals and their respective informants.[28] In all three places, the profile of deaths attributed to tobacco smoking was quite different from that which had been expected on the basis of indirect methods. In South Africa, for example, the leading three causes of death attributable to smoking were found to be chronic obstructive pulmonary disease (COPD), tuberculosis, and lung cancer (in decreasing order). In China, there is significant variation in mortality from lung cancer and COPD in non-smokers (due to indoor pollution and other factors). Tobacco seems to amplify these rates. An amplification of tobacco-attributed mortality rates across different ethnic groups was not observed in New Zealand, suggesting that the tobacco epidemic may behave differently in different populations.

In Washington state in the United States, a question on smoking was added to death notification forms in 1988,[29] but, unfortunately, very little use was made of the data. This question was subsequently reworded as "Did smoking contribute to this death?", in keeping with similar questions used in other states. We believe this approach leads to serious biases in the estimation of tobacco-attributable deaths, because medical practitioners completing death notification forms would have difficulty in reliably and directly attributing any single death to antecedent external events such as use of tobacco.[26] Thus, asking a doctor whether a particular person's death was actually caused by smoking will seriously underestimate the number of deaths that are less obviously associated with tobacco. Unsurprisingly, therefore, although a subsequent study in Oregon derived reasonable estimates for deaths attributable to lung cancer, the numbers of deaths attributed to tobacco from other tobacco-related diseases were lower than expected.[30]

We propose that including questions on the smoking status of the deceased on the death notification form would provide invaluable, contemporary and precise information to monitor the current state of the tobacco epidemic, and its evolution over time. It would also provide direct local evidence on the benefits of quitting (something that, again, indirect approaches cannot reliably do). Questions would ideally ascertain whether deceased people had "ever" smoked and, if so, the age at which they stopped. With careful wording and appropriate options for refusal by the family informant to answer, the information obtained could be used to estimate key epidemiological parameters, using standard case–control methods. Better still, if such questions about their smoking status were also asked of the next-of-kin or family informant, a living control group would be established for comparison purposes after matching for sex.[27,31]

Using PubMed, we found 23 articles about the accuracy of epidemiological information provided by "proxy informants". Among several questions asked in a range of epidemiological studies, modest questions on tobacco consumption, like the ones we suggest, were found to be the most reliably answered.[32-34]

Conclusion

Australia has an excellent and efficient system of death registration, involving complete notification of the event of death and certification of the cause of death by a medical practitioner. Additional questions are completed by the funeral director. Concerns about privacy have been raised, but the next-of-kin or family informants are already being asked mandatory questions about personal details of the deceased (such as place of birth, Indigenous status, and names of the mother and father of the deceased). Thus, inclusion of additional questions about the smoking status of the deceased (eg, ever smoked and age stopped) and the informant's own smoking status (with an option to refuse) could be readily integrated into this procedural requirement of the doctor or the funeral director. Any potential problems relating to the legal status of this form can be overcome by minor changes in regulations and a statement undertaking that the data would be used "for statistical purposes only". Some registrars of Births, Deaths and Marriages have raised practical concerns about any changes to the existing information systems. The amendments we describe would only require very modest modifications, yet their value for public health would be enormous.

Our proposal requires the support of the state and federal Attorneys-General, the state and territory registrars of Births, Deaths and Marriages, the medical profession and, importantly, funeral directors. The latter perform many of the necessary, often invisible administrative and cultural functions for deceased people and their families. Their important contribution to the vital statistical record is often underestimated. Implementing our proposal would substantially enhance the evidence base for tobacco control in Australia.

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Competing interests

None identified.

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