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Editor,
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Dear Editor,

Issues with the Acute Stroke Registry Malaysia

We were pleased to see the publication of the article by Aziz et al. detailing the acute stroke registry in Malaysia.[1] Basic information on incidence is sorely needed. Unfortunately there are significant issues with the research; and we are now in the frustrating position of having data for which there are outstanding questions about its validity.

The first and most obvious problem can be seen in Table 3. The age standardised rates (WHO population) for ischaemic stroke increased almost three-fold over a five year period from 2010 (44.94) to 2014 (126.35). The increase looks dramatic, until, one realises that the 2010 (and probably 2011, 2012 and 2013) rate is too low to be credible, based on all other available, relevant data. Globally, there is no significant stroke incidence study post-2000 using (WHO) age standardised rate with an incidence less than 117 per 100,000 (95%CI: 87.8–152.6).[2] If Malaysia were a “poster-child” for health promotion one might seek an explanation there; however, as early as 2006 the National Health and Morbidity Survey showed a high prevalence of obesity, male smoking, hypertension, and diabetes – a profile of risk factors incompatible with a low stroke incidence.[3]

A closer reading of the paper raises more questions. The authors write of a pilot study in two states.[4] It was actually a pilot study in two hospitals, one in each state. That published pilot study paper reported results from August 2009 to December 2010 overlapping with the non-pilot study data from year 2010. This is 20% of the total observation time from the years 2010-2014. We are now left wondering when the other hospitals in each state joined the registry. Did they join during the pilot study in 2010 or later? This will affect case ascertainment significantly. Each of the 13 states, furthermore, has multiple hospitals. Did the registry only operate in one of the hospitals in each state (like the pilot study) or all the hospitals in each state? Terengganu, for instance, one of the pilot study states has six Ministry of Health hospitals, when did the other five join? What was the likely proportion of stroke cases missed if the registry only operated in some hospitals? If more hospitals were brought on line over time, could this account for the increase in the stroke incidence in Table 3?

Table 1 presents the basic demographic information of the patients recorded in the stroke registry. We are told in the text that n=7,668 (7,830 registered patients of whom 162 were excluded from the pilot study). None of the participant numbers (by demographic category) in the table sum to 7,668: Gender n=7,354; Ethnicity n=7169; Marital status n=6,955; Education level n=5,901; Occupation n=6,495. Missing data are very common in registry data, and need to

be reported. Readers, however, cannot know if the data are missing or there is something more fundamentally wrong in the reporting. There are similar problems in Table 5 (clinical outcomes). Less than half of the registered strokes (n=3,606) record information on the location of the stroke, only 64% (n=4,911) record information on the level of neurological deficit.

Registries are critical for surveillance and monitoring of morbidity either through hospitals or at the population level. They are also resource intensive to establish and maintain to a high standard; an outcome that can take several years to achieve. The Stroke Registry is an enormously important initiative, and the authors should be congratulated for the work. However, the utility of the data is severely curtailed without proper reporting of the methods of data collection and analyses. This shortcoming contributes to confusion rather than knowledge. We look forward to the next iteration.

Yours faithfully,

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