

Executive summary

This report forms an addendum to *Morbidity of Vietnam Veterans: A Study of the Health of Australia's Vietnam Veteran Community: Volume 3 Validation Study* (AIHW 1999), which validated a series of health conditions reported by Vietnam veterans in an earlier Morbidity Study (DVA 1998) about themselves and their children. During the conduct of this validation study, it was found that the time required to complete the validation of multiple sclerosis (MS) and motor neurone disease (MND) in veterans would have seriously delayed the release of the Validation Study report. Therefore it was recommended that the validation of these two conditions be undertaken as a subsequent study.

The aim of this study is to medically confirm self-reported cases of MS and MND among Vietnam veterans who participated in the Morbidity Study, and to compare the number of validated conditions with the number of expected conditions based on Australian community standards.

The Australian Institute of Health and Welfare (AIHW) conducted this Validation Study under the direction of a Study Advisory Committee that included ex-service representatives. An Expert Neurologist Panel convened by AIHW assisted the study.

The methodology used in this report to validate reported cases of MS and MND consisted of the following four stages:

- obtaining the veterans' permission to validate the condition(s) they reported in the Morbidity Study by contacting their relevant doctors;
- contacting the veterans' general practitioners for their opinions on the presence of MS or MND, and requesting the names of the veterans' neurologists;
- contacting the veterans' neurologists to request copies of clinical notes relevant to the diagnosis of MS or MND; and
- having these clinical notes assessed independently by the Expert Neurologist Panel according to internationally accepted diagnostic criteria: the Rose criteria for MS and the El Escorial criteria for MND. These criteria allow each case to be classified as either definite, probable, possible or 'does not have the condition'. Under the rules of the Rose and El Escorial criteria, only definite and probable cases are considered validated.

Response rates from veterans in this study were considered acceptable for statistical validity. In the original Morbidity Study 209 veterans reported that they had either MS or MND, and 145 (69.4%) replied to this follow-up study. The response from medical practitioners was excellent, with 98% of general practitioners and 96% of neurologists responding to requests for information about veterans' conditions.

After all reported cases of MS and MND were followed up and classified using the four stages outlined above, the number of validated conditions of MS and MND among veterans was substantially lower than the number reported in the Morbidity Study (Volume 1). This was believed to be due to misinterpretation of the terms MS and MND by veterans, particularly MND.

When the number of validated cases of MS and MND among veterans was compared with the expected number of conditions, based on the Australian community standard, no statistically significant difference was found between the prevalence of MS and MND in veterans and that of the general Australian community.

However, if reported cases of MND among deceased veterans are included as 'validated' where clinical notes were not available but MND is included as a cause of death on the death certificate,

the estimated number of cases among veterans is at the upper limit of the 95% confidence interval for the Australian community standard.

It is recommended that caution be used in the interpretation of the MND results. The estimated Australian community standard for MND used in this study is considered to be the most accurate estimate possible, but it should be understood that a number of assumptions were made in calculating this standard (Section 3.3, page 15). These assumptions introduce a level of uncertainty that cannot be measured statistically, but they were necessary because of the lack of prevalence data for MND in Australia. Any margin of error in these assumptions will affect the Australian community standard, and may have the potential to change the conclusion that there is no difference between the prevalence of MND in veterans compared with the Australian community standard.

In the case of MS, the number of validated conditions among veterans is well within the 95% confidence interval for the community standard. Therefore variations in the assumptions are unlikely to affect the conclusion of no statistically significant difference between the prevalence of MS for veterans and the Australian community standard.