

1 Purpose, organisation and management

1.1 Introduction and background

Vietnam veterans have been studied in Australia and overseas, with a view to establishing how service-related experience has affected their health and wellbeing. Several key health-related studies in Australia have been published relating to herbicide use, medication use, and post-service health status and mortality patterns. These published studies include Morbidity of Vietnam Veterans Volume 1 (DVA 1998a), Mortality of national service Vietnam Veterans: A report of the 1996 retrospective cohort study of Australian Vietnam veterans (Crane et al. 1997), Australian Vietnam Veterans Health Study (O'Toole et al. 1996), Dapsone exposure, Vietnam service and cancer incidence (AIHW 1992), and Australian Veterans Health Studies Parts 1–3 (Fett et al. Forcier et al and O'Toole et al. 1984). Each of these studies has shown some ill effects of war experience on veterans, though some of their findings have not always been conclusive or consistent. Collectively, these studies have suggested a pattern of ill health that has led to calls for further research in the area and for government policy response to assist those affected.

The Morbidity Study (DVA 1998a) focused not only on the health of male veterans but also on the health of their children. It surveyed 49,944 male veterans about their own and their children's health – 40,300 veterans responded, and the findings suggested that among male veterans there were high prevalence rates of the following:

- particular cancers – prostate, colon, testis, breast, lung, eye, head and neck, skin (melanoma), leukaemia, soft tissue sarcoma and non-Hodgkin's lymphoma
- multiple sclerosis and motor neurone disease
- mental health conditions – panic attacks, anxiety disorders, depression and post-traumatic stress disorder (PTSD)
- skin conditions – dermatitis and eczema
- ischaemic heart disease and high blood pressure
- asthma
- diabetes.

Among male veterans' children, there were high prevalence rates of:

- cancers – leukaemia, Wilm's tumour, nervous system
- congenital anomalies – spina bifida, anencephaly, Down syndrome, tracheo-oesophageal fistula, cleft lip or palate, absent or extra body parts and other abnormalities
- deaths due to illness, accident and suicide.

These reported excess prevalence rates were based on self-reports by veterans and a comparison with estimated Australian community standards. Note that some conditions reported by veterans in the Morbidity Study (i.e. impotence in veterans and hearing loss

and sight problems in children) showed significantly lower prevalence rates than expected based on the Australian community standards.

The Morbidity Study relied on self-reported information provided by veterans about conditions affecting themselves and their children. However, there are known difficulties in the interpretation and validity of self-reported health data. Bergmann et al. (1998) indicated that, when self-reported health conditions were validated against medical records, there are some conditions which are 100% accurate whereas others show some variability in the quality of reporting. They concluded that 'investigators should be aware that errors in the reporting on conditions can create considerably more misclassification if outcomes are based on self reports only' (Bergmann et al. 1998:975). This misclassification can be in the form of respondent bias (individually or systematically driven) or respondent error (particularly in relation to medical terminology). Given this potential bias, it is important that the use of these data be consistent with the quality of the data.

In order to build policy, the quality of the data must be ensured. Therefore, it was recommended in the Morbidity Study that 'if practicable a single integrated validation exercise be undertaken and that appropriate levels of support be offered to those undergoing validation' (DVA 1998a:11).

This recommendation was considered by the Minister for Veterans' Affairs (the Honourable Bruce Scott MP) who subsequently announced that a study to validate a selected set of medical conditions would be undertaken as recommended.

This validation study would estimate the extent of selected medical conditions by confirming each of the selected veteran-reported conditions. Medical practitioners and community registers of medical information, such as death and cancer registrations, were proposed to validate the reported conditions.

1.2 Purpose of the Validation Study

This study, known as the Validation Study, has two main purposes:

- to medically confirm selected self-reported medical conditions in male veterans and their children; and
- to compare the number of validated conditions with the number expected based on Australian community standards, as identified in the Morbidity Study report.

In veterans, the selected medical conditions included all cancers and degenerative diseases of the nervous system. In veterans' children, the conditions included congenital abnormalities, cancers and deaths. These conditions are listed in detail in Chapter 2.

The information gained from this study will be used to assess the health status of veterans and their children and to help develop policy to assist these people.

1.3 Study organisation and administration

This study was commissioned and funded by the Department of Veterans' Affairs (DVA). It was conducted by a project team (Appendix 1) at the Australian Institute of Health and Welfare (AIHW) under the *Australian Institute of Health and Welfare Act 1987*. The study was planned under the supervision of a Study Advisory Committee, gained ethical approval, and was guided by the advice of a medical advisory panel. A project team at DVA also assisted in the development of the project.

1.3.1 The Study Advisory Committee

The Study Advisory Committee, including representatives of Ex-Service Organisations, and staff from DVA and AIHW (Appendix 2), were responsible for the conduct of this study. The committee provided an opportunity for debate on issues relating to the study methods, provided feedback from veterans, advised on modifications to the operational protocol, and assisted in promoting the study. The committee met regularly during the course of the study and was chaired by Major General Paul Stevens, Repatriation Commission. At no time did this committee review information or have access to data that could identify individuals in this study.

1.3.2 Ethics Committees

All protocols for study operations were reviewed and approved by the AIHW and DVA ethics committees. Additional approvals were also provided by State and Territory cancer registry ethics and data review committees in relation to specific aspects of the project. These submissions were to ensure that the linkage of the veterans' and veterans' children's names against the National Cancer Statistics Clearing House (NCSCCH) and the State and Territory cancer registries was appropriate.

Project materials (e.g. survey forms and letters) were also put before DVA's privacy officer who provided opinion on their potential impact and any potential conflict they may have with the *Commonwealth Privacy Act 1988* Information Privacy Principles.

1.3.3 Medical Advisory Panel

The Medical Advisory Panel (Appendix 3) met several times to review medical issues relating to the study. Its terms of reference were to:

- assist the AIHW's project team with issues and decisions that require technical medical knowledge;
- define and apply criteria for motor neurone disease and multiple sclerosis;
- resolve areas of medical uncertainty relating to validation of individual cases (with or without external expert help); and
- help liaise with medical practitioners and independent experts for the purposes of the study.

At no time did the panel review information that could identify individuals in the study. Two sub-panels were also established to examine issues relating to multiple sclerosis and motor neurone disease.

1.4 Structure of this report

Chapter 2 provides a detailed report on the methods used in the Validation Study.

Chapter 3 presents the results of the validation process. A discussion of the strategies adopted to maximise response rates, and the final response rates achieved, are also provided here.

Chapter 4 provides a discussion of the results of the Validation Study. It also examines the limitations of the study and presents its conclusions and recommendations.

The Appendixes contain samples of the various forms, letters and protocols used to support this study.