

# **Morbidity of Vietnam veterans**

**A study of the health of Australia's  
Vietnam veteran community  
Volume 3 Validation study**

The Australian Institute of Health and Welfare is an independent health and welfare statistics and information agency. The Institute's mission is to inform community discussion and decision making through national leadership in the development and provision of authoritative and timely information on the health and welfare of Australians.

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**Australian Institute of Health and Welfare**

Australian Institute of Health and Welfare  
Canberra

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REPATRIATION COMMISSION

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10 November 1999

The Hon Bruce Scott MP  
Minister for Veterans' Affairs and  
Minister Assisting the Minister for Defence  
Parliament House  
CANBERRA ACT 2600

Dear Minister

As Chairman of the Advisory Committee for the validation of the results of the Vietnam Veterans' Health Study, I am pleased to forward the report entitled "Morbidity of Vietnam Veterans: A Study of the Health of Australia's Vietnam Veteran Community. Volume 3. Validation Study." for your consideration.

This is the third and final volume of the study of the health of Vietnam veterans begun in 1997. Its findings are vital but do not stand alone. Because of the manner in which the Health Study evolved, the total findings are to be found by reference to each of the three Volumes. The findings of the Health Study also complement the results of two previous studies: "Dapsone Exposure, Vietnam Service and Cancer Incidence" (AIHW, Canberra, 1992) and "Mortality of Vietnam Veterans: the Veteran Cohort Study" (DVA, Canberra, 1997).

In Volume 1 of the Health Study, male Vietnam veterans rated their own health as very poor and reported a number of conditions, especially psychiatric conditions, at a prevalence that exceeded the community norm. They also reported in approximately 30 per cent of cases that their own health problems had led to health problems in their partners, and that their children apparently suffered a greater prevalence of death, cancer and congenital abnormality.

One of the recommendations from Volume 1 was that some conditions – cancers, motor neurone disease and multiple sclerosis in veterans; and some cancers, genetic abnormalities and deaths in veterans' children – should be subject to validation at the level of a medical diagnosis or inclusion on a medical register. Validation would provide an accurate and reliable prevalence of each of these conditions as the basis for consideration of policy change, and as the basis for any future study into causation. The validation project is the subject of Volume 3.

Volume 2 of the Health Study reported the results of the survey of female Vietnam veterans, their partners and children. Here again, the female veterans reported their health as poorer than the general community, but not to the same extent as male veterans. Fourteen per cent reported their poor health had affected the health of partners. The female veterans did not report problems in children that exceeded expected levels, but the number of veterans responding was perhaps too small (223 as opposed to 40,030 male veterans) to constitute a statistically viable sample for this purpose.

The validation that is reported in Volume 3 commenced in October 1998 and has taken just over a year to reach a conclusion on the majority of conditions examined. Reports on multiple sclerosis and motor neurone disease are yet to be produced because the difficulty of diagnosis in these conditions means that some of those identified as potential sufferers will need to be examined by a small group of specialists to ensure accuracy. The results for multiple sclerosis and motor neurone disease will be published as an addendum to Volume 3 at a later date. Meanwhile, it should be noted that the prevalence of motor neurone disease identified through deaths of veterans and accepted DVA claims suggests a potential increase compared to community norms.

The Validation Study has taken longer than originally envisaged primarily because its methodology necessitated obtaining responses sequentially from the veterans involved, then from their children if required, and then from doctors or registers. Sufficient responses had to be obtained at each stage to ensure statistically reliable results. Campaigns to follow-up non-respondents were required to obtain the necessary numbers from all groups across the range of conditions. The need for these campaigns progressively delayed the Study's finalisation.

The findings of the Validation Study are shown in this Volume. Some conditions in both veterans and children have been validated as exceeding the community norm, and thus signal a need for an appropriate policy response. The Advisory Committee commends the findings in this report to you.

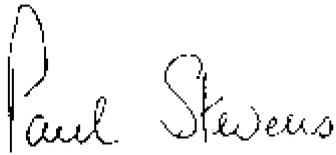
The Advisory Committee also note that some findings of concern from Parts 1 and 2 of the Study could neither be responded to under current Repatriation provisions nor be subject to validation because of the absence of a clear diagnostic category to define the condition, or because of a lack of community data against which it could be compared. The effect of war-related illness in veterans upon their partners and families is a case in point. The Reports of Volumes 1 and 2 recommended consideration of policy responses to these wider findings, and these recommendations are again brought to your attention.

As the Health Study draws to a close there are two further matters of importance.

The first is to note that while the health of Vietnam veterans, their partners and their children has now been examined, this process only began in 1997. Thus all the veterans who died before this date and their children have been excluded from the Health Study. There is an argument that these are the very veterans and children whose health would have been the poorest. The Committee has asked me to bring this to your attention. Your recent announcement of a health study for Gulf War veterans and routine health studies of veterans of future deployments should assist in alleviating this problem in future.

Finally, I would like to take this opportunity to thank all those connected with the Validation Study for their diligence and hard work. The Australian Institute of Health and Welfare conducted the Study and prepared the report. DVA staff assisted the drafting of the protocol for the Study, and participated in and supported the deliberations of the Study Advisory Committee. But principally I would like to thank the ex-service members of the Advisory Committee, Mrs Colleen Thurgar of the Returned and Services League of Australia, Mr John Methven of the Vietnam Veterans' Association of Australia, and Rear Admiral Guy Griffiths of the Australian Veterans and Defence Services Council. Their advice and critical appraisal on behalf of the wider Vietnam veteran community was rigorous and much appreciated.

Yours sincerely

A handwritten signature in cursive script that reads "Paul Stevens". The signature is written in black ink and is positioned below the "Yours sincerely" text.

Paul Stevens  
Chairman, Morbidity of Vietnam Veterans Study  
Advisory Committee and  
Commissioner, Repatriation Commission



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# Executive summary

The Validation Study report is the third and final volume in the Morbidity of Vietnam Veterans series. The first two volumes of the series sought the self-reported health status of all Vietnam veterans and as well as their partner(s) and children. *Volume 1: Male Vietnam Veterans Survey and Community Comparison Outcomes* (Department of Veteran's Affairs (DVA) 1998a) contains the male veteran outcomes, while *Volume 2: Female Vietnam Veterans Survey and Community Comparison Outcomes* (DVA 1998b) contains the female veteran outcomes. One of the recommendations made in Volume 1 was that some conditions (as noted below) should be subject to validation. This volume provides the results of these validations. Its findings should be considered in conjunction with the findings of the series.

Both Volume 1 (the Morbidity Study) and Volume 3 (the Validation Study) deal exclusively with male Vietnam veterans and their children. The results from the Morbidity Study suggested that a higher prevalence of certain self-reported health conditions exist in Vietnam veterans and their children than the general population.

The Morbidity Study (DVA 1998a:10) recommended that the results obtained for the following conditions in veterans be validated as a matter of urgency:

- all cancers (with the exception of non-melanocytic skin cancers)
- motor neurone disease
- multiple sclerosis.

Recommendations of the Morbidity Study (DVA 1997:11) regarding children of male Vietnam veterans were:

- that the responses which, taken together, indicate an increased level of congenital abnormalities in the veterans' children be validated as a matter of urgency;
- that the responses which, taken together, indicate increased mortality rates in the veterans' children be validated as a matter of urgency; and
- that the responses which indicate increased rates of leukaemia, Wilm's tumour and cancer of the nervous system in the veterans' children be validated as a matter of urgency.

The Validation Study aims to medically confirm selected conditions in Vietnam veterans and their children. The results of this process may then be compared with the Australian community standards used in the Morbidity Study to establish whether there is a higher prevalence of these conditions in Vietnam veterans and their children.

The Australian Institute of Health and Welfare (AIHW) ran the Validation Study under the direction of a Study Advisory Committee that included Ex-Service Organisation representatives.

A total of 6,842 veterans were surveyed about conditions they reported in the Morbidity Study that they, or their children, suffered from. From the initial survey 72% of veterans responded giving permission for the study to validate the conditions they had listed. Based on the responses concerning veterans' children, the health of 3,629 children with selected conditions was investigated. Information was provided by 67% of those children surveyed.

Sources used to validate reported conditions were clinicians, the National Death Index (NDI), National Cancer Statistics Clearing House (NCSCCH), Congenital Malformations Register (CMR), DVA database, and documentation provided by the veteran or the veteran's children. Clinicians were requested to provide validation for 1,707 conditions reported by veterans and their children. The response rate from the doctors contacted was 86%. The uses of validation sources are discussed in Chapter 3.

The Validation Study has been able to provide good evidence that indicates a high prevalence of several conditions in veterans and causes of death and conditions in their children. The outcomes of the Validation Study use the community standards derived in the Morbidity Study as a basis. The results obtained depend on the quality of the Morbidity Study estimates.

The results for the veterans are as follows:

- Melanoma of the skin and prostate cancer show significantly higher prevalence in veterans than in the Australian community standard.
- Breast and eye cancer, non-Hodgkin's lymphoma and leukaemia show no significant difference in prevalence between the veterans and the Australian community standard.
- Colorectal cancer, lung cancer, soft tissue sarcoma, and testis cancer show significantly lower prevalence in veterans than the Australian community standard.
- Cancer of the head and neck, other cancers and total cancers do not have a corresponding community standard, and one could not be derived in a way that was compatible with the prevalence data, so no assessment of their significance can be made.
- Motor neurone disease and multiple sclerosis were not addressed in this study. A separate study will be undertaken to validate these conditions.

The results for the veterans' children show:

- Spina bifida maxima and cleft lip/palate show significantly higher prevalence in veterans' children than in the Australian community standard.
- Deaths due to accidents and deaths due to illnesses show significantly higher prevalence in veterans' children than in the Australian community standard.
- Suicides are three times more prevalent in veteran's children than the Australian community standard.
- Wilm's tumour and anencephaly show no significant difference in prevalence between the veterans' children and the Australian community standard.
- Leukaemia, cancer of the nervous system, other cancers, Down syndrome, tracheo-esophageal fistula and absent body parts all show significantly lower prevalence in veterans' children than the Australian community standard.
- Extra body parts does not have a corresponding community standard, nor could one be derived in a way that was compatible with the prevalence data, so no assessment of its significance can be made.

The results from this Validation Study show only a small part of the picture of the health of veterans and their children. The results from this study should be read in conjunction with other studies listed in the references of this document to gain an appreciation of the range of health issues confronting this group of people.

Based on the reliance of the community standards derived in the Morbidity Study, statistical analysis of the Validation Study has prompted the following recommendations. It is recommended that:

- a validation study of motor neurone disease and multiple sclerosis in Vietnam veterans be undertaken as a matter of urgency in order to complete the validation process. This recommendation was made during the life of the Validation Study and is being planned by the AIHW, in conjunction with the Department of Veterans' Affairs, for completion in 2000;
- suicide in veterans' children be further investigated and the result drawn to the attention of the Vietnam Veterans' Counselling Service;
- cancer of the adrenal gland in veterans' children be further investigated and compared to a derived community standard; and
- Morbidity Study and Validation Study data be made accessible under appropriate conditions for use in further studies. Provision for this access is important to further work in this area. Approval for further work using these data would need to be gained from the AIHW Ethics Committee, after liaison with the Commonwealth Department of Veterans' Affairs.



# 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.

# 2 Design and implementation

This chapter sets out the key elements in the design and implementation of the Validation Study. It describes the study population, the conditions being validated and the validation criteria. A description of the survey and how it was conducted is provided, as is a discussion of the problems experienced in its implementation, the effects these had, and how they were resolved.

**For the purpose of the Validation Study, the definition of veteran is a serviceman who was posted to Vietnam who responded to the Morbidity Study.**

## 2.1 Study design

In summary, the study design sought to:

- survey all veterans reporting selected medical conditions in the Morbidity Study;
- obtain the veterans' and, where appropriate, their children's consent to validate their medical condition;
- undertake the validation by surveying medical practitioners or matching reported conditions to disease or death registers; and then
- compare the number of validated conditions with the number expected based on Australian community standards as determined in the Morbidity Study.

The methods used to achieve this study design aimed to:

- ensure the comparability of the results with population-based estimates of disease in the community;
- ensure high participation rates from veterans, their children and their doctors while minimising the impact of the study upon them; and
- ensure the confidentiality of personal information used in this study.

In establishing this study design it was critical to define the criteria by which conditions would be accepted as valid. Although the specific criteria varied slightly among the conditions, the general underlying principles were the same. These principles are set out in section 2.1.4 below.

### 2.1.1 Data considerations

The data that were collected in the Morbidity Study by the survey firm AC Nielsen were used as the basis for the Validation Study. The Morbidity Study was a voluntary survey of the health of all living Vietnam veterans, their spouses and their children. The purpose of this study was to obtain health-related baseline data about Vietnam veterans that could be used for short, medium and longer term policy development.

Data from the Morbidity Study were transferred to AIHW by the DVA and AC Nielsen with Ethics Committee approval and are protected under the *Australian Institute of Health and Welfare Act 1987*. The original survey forms are held in a secure environment with the original data collector, AC Nielsen, and at the completion of the Validation Study will be

deposited with the Australian Archives under the custodianship of the AIHW. The electronic version of the data was transferred to the AIHW, where it has been physically and electronically secured with access restricted to those undertaking the study.

This transfer of data was declared to those completing the Morbidity Study survey by the covering letter to the veteran. This letter stated: 'At the end of the study all source data will be transferred to the Australian Institute of Health and Welfare for safe custody and, in turn, for more detailed analysis of veterans' health status.'

Data generated from this study are protected under the *Commonwealth Privacy Act 1988* and the AIHW Act. Subject to the approval of the AIHW Ethics Committee, and after liaison with the DVA to ensure that the concerns of veterans are respected, this data may be used for further analysis of veterans' health status'.

### **2.1.2 Selecting the Validation Study population**

The population for the Validation Study is a subset of all Vietnam veterans who participated in the Morbidity Study.

The study population used for the Morbidity Study was derived from all male Vietnam veterans on the Nominal Roll of Vietnam Veterans (DVA 1997b), but excluded:

- those who died in service;
- those who died between the end of the Vietnam war and 1997; and
- those whose address could not be obtained from the electoral roll.

The Validation Study population was extracted from the population used in the Morbidity Study, but excluded:

- those who could not be contacted at their last known address or where information about them was incomplete;
- those who did not respond to the Morbidity Study survey; and
- those veterans or their children who did not have a condition selected in the Validation Study.

The Validation Study population therefore comprised 6,842 veterans and their children.

Veterans who had died between the Morbidity Study and the implementation of the Validation Study in September 1998 were identified by matching the Morbidity Study population with the National Death Index (NDI). Matching to the NDI was undertaken using automated matching algorithms or manual search. These algorithms looked for the level of match between the complete name, transpositions of name components, phonetic and common variants of name components, dates of birth and minor variations of these dates. Where a veteran was found to have a corresponding death registration in the NDI, the cause of death, date of death and place of death were recorded where available.

These deceased veterans were considered as non-respondents to the Validation Study survey, except where a death certificate or a record in the NDI provided validation for the reported condition. The children of these veterans were excluded as no address information was available to contact them and it was believed that contacting the widow of the recently deceased veteran could cause emotional distress.

There were 36 veterans whose names were not available from the Morbidity Study data, but whose condition information was consistent with the scope of the study. Though the address information for these veterans was available, it was considered inappropriate to send confidential information to the generic 'householder' in an attempt to contact them.

These veterans' conditions are treated in the analysis as 'not able to be validated' (see definition in section 2.1.4).

Veterans who did not participate in the Morbidity Study, but who subsequently identified themselves and were included in the Validation Study population, are referred to as 'new veterans'. Many of these veterans resided overseas or had incorrect address information at the time of the Morbidity Study. Conditions relating to these veterans are treated separately in the analysis of the validation results (see section 2.3.3).

### 2.1.3 Conditions selected for the Validation Study

The conditions selected for validation in veterans include a number of specific cancers, multiple sclerosis and motor neurone disease. For veterans' children, cancer, various congenital abnormalities and deaths were selected for validation (Table 2.1).

These conditions were selected for validation because it was considered vital that unequivocal evidence be established of the prevalence of each condition. Such evidence is considered essential as a basis for further policy action and a foundation for studies into causality (DVA 1998a).

It is recognised that one veteran or their child may have more than one condition, e.g. melanoma and colon cancer. For the purposes of the Validation Study, analyses will focus on the number and types of conditions rather than the number of veterans affected.

**Table 2.1: Conditions nominated for validation**

<b>Veterans' conditions</b>	<b>Veterans' children's conditions</b>
Head and neck cancer	Leukaemia
Lung cancer	Wilm's tumour
Cancer of the colon	Cancer of the nervous system
Soft tissue sarcoma	Other cancers
Melanoma	Spina bifida
Cancer of the prostate	Down syndrome
Male breast cancer	Tracheo-oesophageal fistula
Cancer of the testis	Anencephaly
Cancer of the eye	Cleft lip/palate
Non-Hodgkin's lymphoma	Absent body part
Leukaemia	Extra body part
Other cancers	Death by accident/other
Multiple sclerosis (MS)	Death by illness
Motor neurone disease (MND)	Death by suicide

A requirement of the study protocol was to separate leukaemia into its four major sub-classifications (acute and chronic lymphatic leukaemia, and acute and chronic myeloid leukaemia) and spina bifida into its two main types (maxima and occulta). These disease sub-types have distinct risk factors that may be related to particular exposures during war service. The clinically significant form of spina bifida is maxima, whereas occulta is often only diagnosed during the investigation of other health complaints, e.g. back injury. For most of these conditions, the separations were achieved. However, some validation reports were not able to be definitive on this classification.

During the validation process, it was found that a high number of the reported cancers of the colon were actually cancer of the rectum. The Study Advisory Committee decided that the cancers of the rectum should be combined with the cancers of the colon to make a colorectal cancer category. As these two cancers were not considered together in the Morbidity Study, an Australian community standard was not available. This meant that a new community standard for colorectal cancer needed to be derived. The AIHW achieved this using the computer software program called DISMOD<sup>®</sup> and the method is outlined in Appendix 16.

During the conduct of this study, it was found that the validation of MS and MND and their classification into possible, probable and definite categories was too difficult to achieve in the available time frame. This was due to the need to obtain detailed medical data rather than a simple diagnosis, with the possibility of further clinical assessment for some veterans. In order to remedy this situation a separate study is being conducted which will review clinical notes and in some circumstances examine veterans, with their consent, to validate and classify their conditions. The information on multiple sclerosis (MS) and motor neurone disease (MND) in this report is limited to those cases where a definite confirmation is evident from the information available (mostly death certificates).

#### **2.1.4 Validation procedures**

Validation of the conditions and causes of death reported in this study require them to be allocated to a validation category based on the evidence provided by a validation source.

A validation source is defined as the provider of medical information that can confirm the existence of a condition. The validation sources used in this study are:

- medical documents (e.g. pathology results)
- doctor's certification (e.g. a response to a validation study questionnaire or a standard doctor's certificate)
- records on a disease or death register.

The validation sources used in this study, the issues surrounding their use, and their application to specific conditions are described in more detail in section 2.3.

In this discussion, the term 'veteran', 'veteran's child' or 'veteran's spouse', or any other reporting source will be replaced by the term 'respondent'. This avoids lengthy repetition of the terminology and avoids the difficulty of defining who completed the Validation Study survey form and who gave the permission for validation to occur.

There are three validation categories used for this study:

##### **Validated**

A condition is considered 'validated' if sufficient information has been provided by the validation source to confirm that the condition currently exists or has existed at some time.

##### **Not validated**

A condition is considered 'not validated' where information received from the validation source indicates clearly that the specified condition does not or has not existed in the respondent to the best of their knowledge. This category also applies where the respondent and their condition does not exist on a disease or death register or where a respondent clearly indicates that they do not have the specified condition.

### **Not able to be validated**

A condition is considered 'not able to be validated' where the validation source nominated by the respondent cannot be contacted or accessed, or where the validation source indicates that it is not able to confirm or deny the existence of the condition. A condition is also considered 'not able to be validated' where the respondent (while acknowledging one condition) fails to either confirm or deny another of their conditions reported in the Morbidity Study.

Where veterans or their children have been sent a survey form and no response has been received, the conditions associated with these veterans or their children are categorised as 'not able to be validated'.

## **2.2 Survey methods**

Veterans, veterans' children and medical validation sources were surveyed using tailored questionnaires. The questionnaires and accompanying information (Appendixes 4–15) were drafted by the project team with the guidance of the Study Advisory Committee. The questionnaires were designed to collect or confirm key elements of information pertinent to the validation and classification of the conditions – name, address, date of birth, condition, validation source, permission to validate and consent signature.

Questionnaires sent to veterans, their children, and validation sources were personally addressed where possible. However, the initial questionnaires directed to veterans regarding their children were not personalised, as little personal information was known about these children from the Morbidity Study.

### **2.2.1 The survey components**

The Validation Study was conducted in several stages summarised in Table 2.2 and described in detail below. This staged approach was necessitated by:

- the requirement to obtain permission from the veterans and veterans' children (where the child was 17 or over, and not under guardianship arrangements) to validate their conditions;
- the need to seek validation information from the nominated validation source or alternatives; and
- the need to raise response rates for various conditions to an acceptable level.

**Table 2.2: Validation Study – survey stages**

Stage	Implementation date	People involved	Information sought	Appendix no. <sup>(a)</sup>
Pilot study	15 September 1998	50 veterans	Veteran confirmation of self-reported condition, validation source, permission.	
Initial mail-out to veterans	14 October 1998	6,842 veterans	Veteran confirmation of self-reported condition, validation source, permission.  Child name and details, condition/death confirmation, child address or veteran permission.	4
First reminder mail-out to veterans	23 November 1998	3,345 veterans	Reminder to veterans to complete the previously supplied survey package.	5
Second reminder mail-out to veterans	9 February 1999	3,306 veterans	Veteran confirmation of self-reported condition, validation source, permission.  Child name and details, condition/death confirmation, child address or veteran permission.	6
Telephone prompting of veterans	16–26 February 1999	1,625 veterans with children, 82 veterans with MS and MND	All veterans who had not responded with living children who have conditions other than absent or extra body parts. All veterans with MS and MND.	10
Mail-out to children Part 1	22 January 1999	498 children	Child confirmation of veteran-reported condition, validation source, permission.	8
Part 2	19 April 1999	303 children		
Reminder mail-out to children	19 April 1999	159 children	Child confirmation of veteran-reported condition, validation source, permission.	9
Telephone prompting of children Part 1	1 June 1999	305 children	All veterans' children who had not returned their survey form.	10
Part 2	19 July 1999	193 children		
Mail-out to doctors for veterans' conditions: Part 1	29 March 1999	251 veterans	Validation of veterans' conditions via nominated doctor.	11
Part 2	25 June 1999	359 veterans		
Part 3	5 August 1999	289 veterans		
Mail-out to doctors for children's conditions: Part 1	26 May 1999	255 children	Validation of children's conditions via nominated doctor.	11
Part 2	5 July 1999	262 children		
Reminder mail-out to doctors	28 June 1999	364	Reminder to validate veterans' conditions.	12
Telephone prompting of doctors	5 July 1999	Related to 303 veterans 92 children	Validation of all outstanding conditions.	13
Telephone calls to veterans who had not reported all children conditions identified in the Morbidity Study	7–8 September 1999	251 veterans	Confirmation of unreported condition.	15

(a) Appendixes are located at the end of this report and contain documentation for each survey stage described in this table.

## The pilot study

The purpose of the pilot study was to test the following elements:

- suitability of the survey form and supporting documentation for veterans
- data preparation and extraction
- mailing house mail merge and delivery functions
- the helpline facility
- response rates
- validation procedures.

The pilot study surveyed 50 veterans whose conditions were reported as cancer. An additional 10 'dummy' names and conditions with AIHW staff addresses were added to the list without the knowledge of the mailing house to test the quality and speed of the delivery system. The pilot survey consisted of a personalised introductory letter from the AIHW, a generic support letter from the Repatriation Commissioner, an information sheet, a number of survey forms corresponding to the number of cancers reported by the veteran in the Morbidity Study, and a reply-paid envelope. The survey forms had printed on them the veteran's name and address, his condition and an identification number.

The response to this survey was positive and therefore survey materials changed little for the main survey. No pilot of the child survey form was undertaken due to time constraints.

## **The Validation Study survey**

The Validation Study survey comprised three separate components:

- An initial survey of veterans, asking for confirmation of any condition they reported for themselves, a signed consent to validate their condition, a validation source, and a confirmation of their contact details. A child survey form was included for each child condition reported in the Morbidity Study. While the number of conditions in the veterans' children was known, attribution of these conditions to a particular child was not possible from the Morbidity Study data. The child survey form requested information on the name, date of birth and sex of each child, and the year and place of diagnosis for each child's conditions to enable validation of these conditions. In cases where the children were aged 17 or over, the child's contact details were requested to enable contact with the child to obtain their permission to proceed with the validation.
- A survey of veterans' children aged 17 and over, seeking their signed consent to validate each condition reported by their father, the year and place of diagnosis and a validation source.
- A survey of doctors and hospitals nominated by veterans and their children as their validation source.

Lower than expected response rates to each of these surveys resulted in a number of follow-up reminders. These reminders were initially mailed out, followed by telephone contact shortly after. Details of the various mail-outs and reminders to veterans, veterans' children and doctors are described below.

### **Survey of veterans**

#### *(i) Initial mail-out*

The initial package sent to veterans consisted of introductory letters from the AIHW and the Repatriation Commissioner, one or more survey forms directed at the veteran and/or his children, an information sheet about the study, and a reply-paid envelope. This package was distributed in October 1998, with almost 7,000 packages sent to the last known address of the veteran. A media release was timed to coincide with this mail-out. The Validation Study survey consisted of the same components as the pilot survey (Appendix 4) with some slight modifications based on feedback from the veterans. Unlike the pilot survey, this mail-out also included the veterans whose children reportedly had conditions requiring validation.

A response time of 3 weeks was allowed for the respondents. Some distribution delays (up to 2 weeks) were experienced in northern Queensland and the north-western areas of

Western Australia. All veterans in these areas, and those veterans contacting the study requiring additional response time, were given an extension.

It was discovered in this mail-out that, due to problems in the original data file, approximately 30 veterans received an incorrect form (i.e. conditions were not specified correctly) or did not receive a children's form when they should have. This problem was fixed by distributing a corrected set of forms with an apology letter.

Responses received from the veterans were entered into a database, date stamped and filed. Although the majority of veterans returned their survey forms completed, some survey packages were returned to the AIHW unopened as the veteran no longer lived at that address. Attempts were made to find alternative addresses from the DVA computer systems or from the *Telstra White Pages* (1999). This work was done by AIHW project staff only and did not involve DVA staff, thereby maintaining confidentiality of the veterans' information. Where this alternative address was also incorrect, the veteran was treated as a non-respondent. Veterans indicating they did not wish to participate in this study or any further study were recorded on the database and their condition allocated a 'not able to be validated' response.

Additional forms were also sent to veterans who had not participated in the Morbidity Study but who had contacted the Validation Study wishing to participate. These veterans were surveyed in the same manner as other veterans, and are referred to as 'new veterans' (see section 2.3.3).

*(ii) First reminder mail-out*

A personalised reminder letter was posted to all veterans (3,345) who had not provided responses by late November (Appendix 5). The letter referred the veteran to the previously supplied survey package and reminded him of the helpline facility. A letter of encouragement from the Minister and veterans' representatives was also included.

This mail-out also took the opportunity to supply corrected or additional forms to veterans who required them.

*(iii) Second reminder mail-out*

The second reminder package was sent to 3,306 veterans who had not responded by the end of January, or whose package was returned to sender. This package contained a letter from the Minister for Veterans' Affairs, with short messages of encouragement from veterans' representatives accompanied by their photographs (Appendix 6). It also contained a reissue of the survey forms, and a media release from the Minister for Veterans' Affairs.

Additional veterans who identified themselves as having one or more of the selected conditions in the Validation Study but who were missed in the original Morbidity Study, or did not respond to that survey, were also sent a package in this mail-out.

*(iv) Telephone prompting of veterans*

As a result of the reminder mail-outs, the response rate for all veterans' conditions apart from multiple sclerosis and motor neurone disease reached acceptable levels. However, the initial response rate from veterans about their children was below the necessary level to provide confidence in the final validation results. Consequently, the Study Advisory Committee advocated the use of telephone prompting for the purposes of improving the response rates. After Ethics Committee approval, telephone numbers were obtained from the *Telstra White Pages* (1999) for selected veterans who had not responded. In following up children's conditions, only veterans whose children were believed to be alive were

contacted, as contacting veterans whose children had died was believed to impose too great a respondent burden. All non-responding veterans who reported multiple sclerosis or motor neurone disease were also contacted.

A team of AIHW staff undertook the telephone prompting. In advance of the prompting, the staff were trained in several areas:

- the study protocols
- the database technology
- techniques in dealing with telephone prompting
- current issues of concern to veterans (study and non-study related).

This training was delivered by the study director and project officer with assistance from a senior counsellor from the Vietnam Veterans' Counselling Service. A protocol for this telephone prompting work was established to assist the staff (Appendix 10).

The telephone prompting team called approximately 700 households between 5.30 p.m. and 9 p.m. (local time) in the period 16–26 February. The telephone prompting sought to establish whether the household was that of a Vietnam veteran, whether the veteran had received the survey package and whether he had difficulties completing the survey, and to offer assistance in completing the package. The staff also offered information about the results of the Morbidity Study and reasons for the Validation Study.

The veterans generally responded positively to the telephone calls. Most indicated that they would complete and return their form soon. Some were concerned that the due date had passed, but they were reassured that their response was still required for the study. Response rates increased substantially after this prompting.

## **Survey of veterans' children**

### *(i) Initial mail-out*

Where responding veterans indicated that they had a child aged 17 or over, and not under guardianship arrangements, a tailored survey package was sent to the child (Appendix 8). This package sought a confirmation of the child's condition, a signed consent to validate their condition, a validation source, and a confirmation of their contact details. The survey package was sent to 792 children in January and April 1999, and to children's guardians in less than 10 cases. The AIHW also complied with veterans' special requests relating to the distribution of survey packages.

### *(ii) Reminder mail-out to children*

A reminder package was sent to 159 veterans' children in April who had not returned their forms from the initial mail-out in January. This package contained a reminder letter addressed to the child of the veteran, an information sheet and a child survey form (Appendix 9).

### *(iii) Telephone prompting*

Approximately 300 veterans' children who had not responded to the survey were contacted by telephone at the beginning of June with a further 200 in July. Their telephone numbers were obtained from notations on their father's survey form or from the *Telstra White Pages* (1999). This telephone prompting focused on children with all conditions excluding those with absent or extra body parts (whose response rate was acceptable) and was conducted using the protocol at Appendix 10. The response of the veterans' children was positive and had the effect of moving the response rate from 44% to 75% within a month.

## Survey of doctors

### (i) Initial mail-outs

In March, June and August, doctors were either faxed or posted a copy of the veterans' and children's survey responses (including their consent), together with a study explanatory letter and a short survey for them to complete (Appendix 11). The doctors' contact details, which were extracted from the veterans' survey forms and the *Medical Directory of Australia* (AMPCO 1998), were personalised on the letter and survey form, and the reported condition was printed on the form. In some instances the doctor was no longer in this listing and further enquiries via *Telstra White Pages* (1999) proved unsuccessful. These cases were allocated to the 'not able to be validated' category.

Doctors were encouraged to return the survey form, and the importance of the study was stressed. They were also offered a standard consultation fee as reimbursement of costs incurred in completing the survey, including the cost of any consultation with the patient in relation to this study. Approximately 100 doctors took advantage of this compensation.

### (ii) Reminder mail-out/telephone prompting

The contribution of doctors in the validation of the veterans' and children's conditions was vital to the success of the Validation Study. Consequently, after an initial poor response rate from doctors, a reminder mail-out of the validation package was undertaken (Appendix 12). This was followed by telephone prompting of approximately 400 doctors (Appendix 13). The doctors or their office staff were alerted to the due date of the survey, to the compensation available and to the importance of the study. Doctors almost always indicated a willingness to assist with the study. The telephone prompting had a significant effect, moving the response rate from 45% to approximately 85%.

### (iii) Self-validation packages

In a small number of cases veterans or their children indicated a willingness to participate in the Validation Study, but did not provide AIHW with the consent to link their records to validation sources or to contact their doctor. In these circumstances, veterans or their children were sent a self-validation package (Appendix 14). This package contained essentially the same materials as those in the doctors' package described above, but it allowed the veteran or their children to visit their doctor and complete the form with the doctor. In these cases an offer was made to the veteran or their child to meet transport and consultation costs.

## 2.2.2 Advertising the Validation Study

The Validation Study was advertised throughout the veteran and general community. A series of press statements from the Minister for Veterans' Affairs was released. These statements covered the study aims and its progress, called for community support, and announced the study's anticipated completion date. Each of these statements had the effect of increasing response rates. Responses were generated not only from veterans eligible for the study but also from those who were not eligible but had an interest in the study and/or the preceding Morbidity Study.

The study was also widely publicised through newsletters (*VetAffairs*, *Veterans' Health*), ex-service organisations (e.g. Vietnam Veterans' Association of Australia (VVAA), National Council and Australian Veterans and Defence Service Council (AVADSC), Returned and Services League of Australia, Vietnam Veterans' Federation of Australia (VVFA)) and on

the DVA web site. DVA representatives provided information and fielded questions relating to the study in its meetings with veterans. Veteran representatives on the Study Advisory Committee also acted as advocates for the study, as did the heads of the veterans' organisations and the Vietnam Veterans Counselling Service. Based on responses received through the study helpline (see below), there was good evidence that information about the study was disseminated effectively through the veteran community networks.

These strategies were used as a broad measure to support the survey, but response rates in particular groups needed to be raised significantly to give the study statistical validity. To provide this boost, telephone prompting of the veterans and their children was undertaken as discussed previously.

### **Helpline**

A freecall helpline was established to provide information to veterans, their families and those interested in the survey. AIHW staff operated the helpline from 9 a.m. until 9 p.m. in the initial stages of the survey and in business hours thereafter. Over 1,000 calls were received, with 80% of calls logged before the end of March 1999. Most calls were less than 10 minutes in length, but some lasted up to an hour.

Most callers to the helpline were positive in their attitude towards the survey. Callers generally fitted into one of several categories:

- reporting other conditions outside the study scope
- reporting new conditions in the study scope
- reporting recent deaths in veterans or their children
- needing clarification on medical terminology
- providing change of address or other details
- checking on the survey return date
- seeking copies of the results from the original study
- wishing to know if a friend had received a form.

In most cases, the outcome of these calls was to send the veteran additional survey forms. In the initial stages of the study, calls were from veterans or their partners, but in the latter stages the majority of calls were from doctors wishing to confirm details about validation procedures.

The helpline had several callers who, unfortunately, were emotionally distressed and in need of further counselling. This counselling was arranged through the Vietnam Veterans Counselling Service in their local area. Occasionally, callers were angry and abusive. However, the staff had been trained to deal with these situations and in many cases the caller was placated. For the most part, callers were friendly, helpful and willing to contribute and gave the study team additional insights into their ill-health, social problems and their Vietnam service.

## **2.3 Validation methodology**

### **2.3.1 Methodology for validation of conditions and causes of death**

The study protocol developed to validate each study condition adopted the following criteria:

- where an appropriate disease or death register is available for the validation of conditions, then it should be used as the 'gold standard' and no further follow-up should occur with alternative sources unless ambiguities were found in the record or the registers;
- for all other conditions, validation should be with doctors nominated by the veterans or their children.

Under these criteria, the primary validation source for deaths is the State, Territory and national death registries; for cancers it is the State, Territory and national cancer registries; and for congenital malformations it is the Congenital Malformations Register (CMR). In the following sections the process of validation using each of these registers and the nominated doctor source is discussed.

### **Validation of death with the National Death Index (NDI) and Registries of Births, Deaths and Marriages**

The NDI, maintained by AIHW, contains identifiable information for all deaths occurring in Australia from 1980. Records prior to 1980 are held by the State and Territory Registries of Birth Deaths and Marriages. Where the respondent acknowledged that the death of a veteran or a veteran's child had occurred, information on the date and place of death was provided by the respondent. Depending on the reported date of death, a comparison of the respondent's personal identifiers was made with either the NDI or a State/Territory Registry of Birth Deaths and Marriages. This comparison was undertaken using automated matching algorithms or by manual search. These algorithms looked for the level of match between the complete name, transpositions of name components, phonetic and common variants of name components, dates of birth and minor variations, sex, and place of diagnosis.

Where a death registration was identified, the cause of death, date of death and place of death were examined. If the cause of death nominated by the respondent was consistent at the International Classification of Diseases, 9th Revision (ICD-9) (WHO 1977), three-digit level with that recorded on the death registries, a 'validated' entry was made on the respondent's record. Where the cause of death nominated by the respondent was not the same as the cause recorded on the death registries, a 'validated – different cause of death' entry was made on the respondent's record. Where a respondent's report of a death was unable to be confirmed on the death registries, a 'not validated' entry was recorded.

The cause of death used by the Validation Study was the underlying cause as coded by the Australian Bureau of Statistics (ABS). This underlying cause may not necessarily reflect the nominated condition for validation, as this condition may have been listed on the death certificate as leading to death but not as the underlying cause. Multiple-cause-of-death data for Australia are available only from 1997, and therefore have not been used in this study. In some instances, this may lead to an underestimation of the number of deaths validated.

Many of the children's deaths reported in the Morbidity Study were not subsequently reported to the Validation Study by veterans, so they could not be validated unless further action was taken. The alternative for validation of these deaths was to extract data from the original Morbidity Study file which listed the veteran's surname, the birth year of his children, their sex and their State of residence. This file was then matched against the NDI using automated matching. The result of this matching was that for surnames which were common (e.g. Smith) there were many potential matches, and identifying the correct death was impossible, so these reported deaths were 'not able to be validated'. For less common names, identifying the correct match was easier and many of these could be validated.

Where the respondent's nominated details of the death were missing or ambiguous, the case was followed up where possible through the respondent's nominated doctor. Where no such doctor was provided by the respondent, an entry of 'not able to be validated' was recorded.

### **Validation of congenital conditions with the Congenital Malformations Register (CMR)**

The CMR is maintained by the AIHW National Perinatal Statistics Unit (NPSU) in Sydney. This register contains de-identified information on major congenital malformations diagnosed in liveborn infants in the first 28 days, or in stillbirths of at least 20 weeks gestation or 400 g birthweight (AIHW NPSU 1998). However, this register contains only data relating to births since 1980, with data for 1980–1981 incomplete in coverage. All of the congenital malformations proposed for validation in this study, with the exception of extra body parts, are included on the CMR, i.e. spina bifida, anencephaly, Down syndrome, tracheo-oesophageal fistula, and cleft lip or palate.

Where the respondent reported a congenital malformation, an assessment of the date and place of diagnosis was made using information provided by the respondent. If this diagnosis date fell within the period of data available through the CMR (1982–1996) a comparison of the respondent's sex, date of birth, and condition was made with the registrations on the CMR.

If the abnormality nominated by the respondent was consistent, at the ICD-9 (WHO 1977) three-digit level, with that recorded on the CMR, a 'validated' entry was made on the respondent's record. Where the abnormality nominated by the respondent was not the same as the type recorded on the CMR, or a respondent's nominated abnormality was unable to be confirmed on the CMR, a 'not validated' entry was recorded.

Where the respondent's nominated abnormality was diagnosed outside the period covered by the CMR, or the date of diagnosis was not provided, the case was followed up where possible through the respondent's nominated doctor. Where no such doctor was provided by the respondent, or the doctor could not be contacted, an entry of 'not able to be validated' was recorded.

### **Validation of cancers with the National Cancer Statistics Clearing House (NCSCH) and State and Territory cancer registries**

The NCSCH is maintained by AIHW, and contains data provided by State and Territory cancer registries on all cases of cancer diagnosed in Australia since 1982. However, for some States and Territories, information is available prior to 1982. Table 2.3 shows the time period covered by each of the State and Territory registers.

Where the respondent recorded that the condition they had was a form of cancer, the date and place of diagnosis was also provided by the respondent. If this diagnosis date fell within the period of data available through the NCSCH or the extended collections of the State and Territory cancer registries, a comparison of the respondent's personal identifiers was made with the cancer registrations. This comparison was undertaken using automated matching algorithms. These algorithms looked for the level of match between the complete name, transpositions of name components, phonetic and common variants of name components, dates of birth and minor variations, sex, and place of diagnosis.

**Table 2.3: Cancer registry coverage**

<b>Cancer registry</b>	<b>Time period covered</b>
New South Wales	1972–1996
Victoria	1982–1996, parts of 1970–1981
Queensland	1982–1996
Western Australia	1982–1997
South Australia	1977–1997
Tasmania	1978–1997
Australian Capital Territory	1972–1996
Northern Territory	1981–1996
National Cancer Statistics Clearing House	1982–1996

Where a respondent was found to have a corresponding registration in the cancer registry, the cancer type and diagnosis date were examined. If the cancer nominated by the respondent was consistent, at the ICD-9 (WHO 1977) three-digit level, with that recorded on the cancer registry, a ‘validated’ entry was made on the respondent’s record. Where the cancer nominated by the respondent was not the same as the cancer type recorded on the cancer registry, a ‘cancer – different primary site’ entry was made on the respondent’s record. In these cases the correct condition was then added to the respondent’s record and validated. Where a respondent’s nominated cancer was unable to be confirmed on the cancer registry, a ‘not validated’ entry was recorded.

Where the respondent’s nominated cancer was diagnosed outside of the period covered by the cancer registries or the date was not provided, the case was followed up where possible through the respondent’s nominated doctor. Where no such doctor was provided by the respondent, or the doctor could not be contacted, an entry of ‘not able to be validated’ was recorded.

### **Validation of conditions with doctors/hospitals/medical records offices**

Where conditions were unable to be validated through any of the disease-based data collections, validation was attempted through the respondents’ nominated doctors, hospitals or other medical records authorities (e.g. Central Army Records Office), hereafter referred to collectively as clinicians. This was undertaken by recording the clinician’s details supplied by respondents and matching these with the *Medical Directory of Australia* (AMPCO 1998) or the *Telstra White Pages* (Telstra 1999) to confirm the practitioner’s current address, telephone and facsimile numbers. Where a suitable level of information was obtained to contact the clinician, a medical validation form was sent to the clinician (Appendix 11). This medical validation form sought from the clinician a clear statement to indicate whether the respondent had ever had the condition nominated, and/or had died from a particular cause. The clinician was also given the opportunity to provide additional comment, or alternative conditions or causes of death to that originally nominated by the respondent. Where the clinician confirmed the condition, a ‘validated’ entry was made on the respondent’s record. Where the condition/cause of death nominated by the respondent was not the same as that recorded on the medical validation form, a ‘not validated’ entry was recorded. If the clinician was unable to indicate whether the condition/cause of death occurred, a ‘not able to be validated’ entry was recorded on the respondent’s record.

As a final validation strategy, DVA claims records were examined for all veterans whose conditions were unable to be validated through the various medical registers or nominated

doctors/hospitals/medical records offices. This examination was undertaken by AIHW staff, and did not involve DVA staff examining individual veteran records.

### 2.3.2 Issues relating to the validation of specific conditions

Veterans often reported multiple conditions. Each condition in this study was treated separately for validation purposes. Table 2.4 provides a description of the number of conditions veterans reported. It is possible that veterans may have given more than one report about the one condition in the Morbidity Study, e.g. melanoma and cancer of the head and neck, which would tend to increase the number of conditions not validated.

**Table 2.4: Number of conditions reported by veterans**

Number of conditions	Number of veterans
1 condition	3,884
2 conditions	1,320
3 conditions	123
4 conditions	23
5 or more conditions	3

The major reason for conditions reported in the Morbidity Study being 'not validated', was the misinterpretation/misallocation of conditions by veterans, often due to the misinterpretation of the medical terminology.

Table 2.5 provides a range of examples of this misallocation.

Some notable examples of misinterpretation/misallocation were:

- non-melanocytic skin cancer instead of melanoma
- rectal cancer instead of colon cancer
- any intellectual disability instead of Down syndrome
- scoliosis or curvature of the spine instead of spina bifida
- benign tumours instead of malignant tumours.

The misallocations were discovered from respondent notations on survey forms, on investigation of the condition with validation sources, and through discussions with respondents on the helpline.

The net result of these misallocations was to reduce the number of reports on certain conditions. However, this was balanced in part by some of these reports being reallocated to their correct condition if they remained of interest to this study. Those conditions that were discovered to be outside the scope of this study were not considered.

One of the more common misallocations was that of cancer. Whereas the validation source and the community standards refer to the primary site (or first site of occurrence) of the cancer, some veterans indicated where the metastases (or spread of the cancer) had occurred. These cases were reallocated to their primary site classification and validated. For example, a veteran may have reported bone cancer, but the primary cancer was in the lung. Some cancers were also misallocated in the Morbidity Study, e.g. mesothelioma of the pleura to lung cancer, and Hodgkin's disease to non-Hodgkin's lymphoma. In the Validation Study, these cancers were reallocated to the 'other cancers' group so as to be comparable with the community standards.

Among children's conditions, the misinterpretation of certain conditions resulted in a substantial number of conditions that were reported in the Morbidity Study not being reported in the Validation Study. This issue was investigated and resolved by telephoning veterans (where permission was given to contact veterans for further information), and asking whether any of their children had suffered the condition reported in the Morbidity Study.

**Table 2.5: Self-reported conditions misallocated to study conditions**

<b>Study condition</b>	<b>Alternative conditions misallocated</b>
<b>Veterans' conditions</b>	
Head and neck cancer	Cancer of another primary site or benign tumour, non-melanocytic skin cancer (e.g. basal cell carcinoma, squamous cell carcinoma), sun cancer, solar keratosis, sun spots
Melanoma	Cancer of another primary site or benign tumour, non-melanocytic skin cancer, sun cancer, solar keratosis, sun spots
Soft tissue sarcoma	Cancer of another primary site or benign tumour, non-melanocytic skin cancer, sun cancer, solar keratosis
Lung cancer	Cancer of another primary site or benign tumour, mesothelioma
Cancer of the colon (bowel)	Cancer of another primary site or benign tumour, cancer of the rectum, Crohn's disease
Male breast cancer	Cancer of another primary site or benign tumour, non-melanocytic skin cancer, sun cancer, solar keratosis
Cancer of the testis	Cancer of another primary site or benign tumour
Cancer of the prostate	Cancer of another primary site or benign tumour, benign prostatic hyperplasia
Non-Hodgkin's lymphoma	Cancer of another primary site or benign tumour
Leukaemia	Cancer of another primary site or benign tumour, anaemia, high white cell count, any blood disorder
Other cancers	Benign tumour
Multiple sclerosis	Devic's disease, scoliosis, atherosclerosis, cirrhosis of the liver
Motor neurone disease	Post-traumatic stress disorder, any nervous disorder
<b>Veterans' children's conditions</b>	
Wilm's tumour	Cancer of another primary site or benign tumour
Leukaemia	Cancer of another primary site or benign tumour, anaemia, high white cell count, any blood disorder
Spina bifida	Scoliosis, curvature of the spine, hydrocephalus, any other congenital malformation, any other spinal condition
Down syndrome	Any other intellectual disability
Anencephaly	Hydrocephalus, encephalitis, any other congenital malformation
Tracheo-oesophageal fistula	Tonsillitis, throat problems
Absent body part	Hole in the heart, missing teeth, missing vertebra or disc, missing tonsils, reduced size organs, any congenital malformation, amputation, excision
Extra body part	Enlarged organs, any congenital malformation
Cleft lip/palate	Any other congenital malformation
Death by suicide	Accident, drug overdose
Death by accident/other	Abortion, stillbirth, sudden infant death syndrome
Death by illness	Suicide

A difficult area for condition allocation was in relation to absent and extra body parts. There are no international criteria to describe the types of organs or body parts involved, or the severity of the condition. For absent body parts, the community standard used in the Morbidity study was based on 'limb reduction defects' reported in *Congenital Malformations, Australia 1995* (AIHW NPSU 1998). 'Limb reduction defects' are

characterised by total or partial absence or severe hypoplasia of skeletal structures of the limbs (AIHW NPSU 1998). To enable valid comparison with the community standard, the definition of absent body parts in the validation process was restricted to conditions of the arms and legs.

In the case of extra body parts, no community standards are available to enable an assessment of any difference in the prevalence between the general population and the veterans' children. This study took a conservative approach whereby, in order to validate the condition, it had to be a significant extra body part. These parts were divided into digit, limb, organ or system where the deformity:

- causes significant impairment or a reduction in function, or
- requires significant treatment or management to be corrected, or
- poses a significant risk to life.

These criteria therefore exclude conditions such as missing teeth or an enlarged organ.

### **2.3.3 'New veterans' and 'new conditions'**

During the course of the study, a number of male veterans who had not participated in the Morbidity Study survey came forward to offer their information. Additional survey forms were forwarded to these veterans and subsequently to their children. These veterans, for the purposes of this study, were termed 'new veterans'. In some instances, veterans who participated in the Morbidity Study reported conditions that they and/or their children had developed since that study. These conditions were termed 'new conditions'.

Although information on 'new veterans' and 'new conditions' has been recorded in the study data systems, it has been treated separately in the analysis (see section 3.2.5) to prevent biasing the results of this study. Bias would be introduced into the results because conditions reported by 'new veterans' are not considered representative of the total veteran population. The reason 'new veterans' have contacted the Validation Study is because they have had one or more conditions diagnosed. 'New veterans' could be included in the validation results only if all living veterans not in the Morbidity Study were included in the calculation of the prevalence rate. Similarly, 'new conditions' could be included in the analysis only if 'new conditions' were obtained from all living veterans, rather than only the Validation Study population.

### **2.3.4 'Extra conditions'**

Some veterans who participated in the Validation Study identified additional conditions that were diagnosed prior to, but not reported in, the Morbidity Study. For example, they may have reported melanoma in the Morbidity Study, but reported melanoma and colon cancer in the Validation Study. In these cases, the additional condition is referred to in the Validation Study as an 'extra condition'. If this 'extra condition' was found to have been diagnosed prior to the 1997 survey, it was assumed that the veteran 'should have' reported it to the Morbidity Study. The condition was therefore added to the reported conditions and validated for the purposes of this study.

### **2.3.5 Non-respondents and 'not able to be validated' responses**

As with most surveys, there were a number of non-respondents to the Validation Study survey. A similar situation arose with those veterans and their children who did respond,

but whose response relating to their condition was not able to be validated. There are several ways in which conditions related to non-respondents, and those not able to be validated, can be dealt with.

Five models dealing with this issue were considered in the analysis of the results. The impact of these models is discussed in Chapter 4. Initially the Study Advisory Committee recommended a fairly general approach by reallocating both the non-respondent conditions and conditions not able to be validated proportionally between the validated and non-validated responses (Model 5). However, in reviewing the results of the survey, it was found that the non-response component was larger than expected and would have a significant impact on estimating the number of validated conditions. This model was difficult to sustain given the lack of knowledge about the likelihood of validation in this group. This lack of knowledge reduced confidence in this model, so alternatives were considered which adopted a more conservative approach. These alternatives are discussed in section 4.4. Model 3 was adopted for reporting purposes and is described below.

In Model 3 the conditions that were not able to be validated are proportionally allocated between the validated and not validated conditions as it is assumed that they would have the same distribution as the validated and not validated conditions. The non-respondents are not counted towards the number of validated conditions because not enough is known about them to make any assumption as to the distribution of their conditions as validated and not validated.

There are many explanations why veterans or their children did not respond to the survey which include:

- veterans or their children were not able to be contacted (e.g. moved residence, overseas)
- veterans were too ill or had died recently
- veterans believe they had stated their condition or that of their children satisfactorily to the Morbidity Study and should not have to do so again
- veterans or their children do not have the condition.

The first three of these explanations imply that the non-respondents were unable to return their forms and so probably had a similar distribution to the responders. Only the final explanation suggests that the non-respondents differed from the respondents in that it suggests all of the respondents did not have the condition they reported in the Morbidity Study. Because we do not know which of these explanations or combinations of these explanations are the truth, we cannot adequately redistribute this group.

The impact of this model is to reduce the number of validated conditions to a level where there is confidence in the result. It is a minimalist position, where any subsequently validated conditions from the non-respondent group can only add to the overall number of validated conditions. This ensures that conditions found to be elevated above the Australian community standard, as derived in the Morbidity Study, are in a position which would demand recognition as significant health problems in veterans or their children.

Deaths in veterans' children were treated differently to the other conditions. Since a method could be adopted that allowed the linking of the non-respondents with the NDI (section 2.3.1), then any death that could not be matched is placed in the 'not able to be

validated' category. These have been allocated proportionally between the validated and not validated responses.

### **Non-response to specific children's conditions**

In a substantial number of cases, children's conditions reported by veterans in the Morbidity Study were not reported to the Validation Study. To resolve these anomalies, veterans were telephoned, where they had given permission to contact them again, and asked whether any of their children had ever suffered from these conditions (Appendix 15). In 90% of cases, veterans reported that none of their children had ever suffered from the previously reported condition(s) and the condition was consequently marked 'not validated'. This situation was consistent across all children's conditions. The most common reasons provided by veterans for the difference in responses between the two studies were that they had been incorrectly reported in the Morbidity Study, or that they had misunderstood the meaning of the condition in the Morbidity Study. Conditions that were acknowledged by the veterans as existing progressed through the normal validation procedures.

For those veterans not able to be contacted by telephone, an adjustment was made on a similar basis to the results of the telephone follow-up, with 90% of conditions marked 'not validated'.

# 3 Results

The results of the study are presented in the following tables, figures and descriptive text. They are divided into several parts reflecting the processing of the survey, the types of responses, and a comparison with the community standards after adjustments for non-response.

## 3.1 Survey response

An important part of the study is the level of response to the survey. In order to provide sufficient confidence in the results, the response rates must be strong, the data quality high and biases minimised or eliminated.

Considerable resources were allocated to achieve satisfactory response rates. These involved a series of mail-outs and telephone reminders which prompted veterans, veterans' children (those aged 17 and over), and doctors to complete their survey forms. The follow-up procedures and response rates for veterans' conditions, children's conditions and doctors are discussed separately below.

### 3.1.1 Veterans' conditions

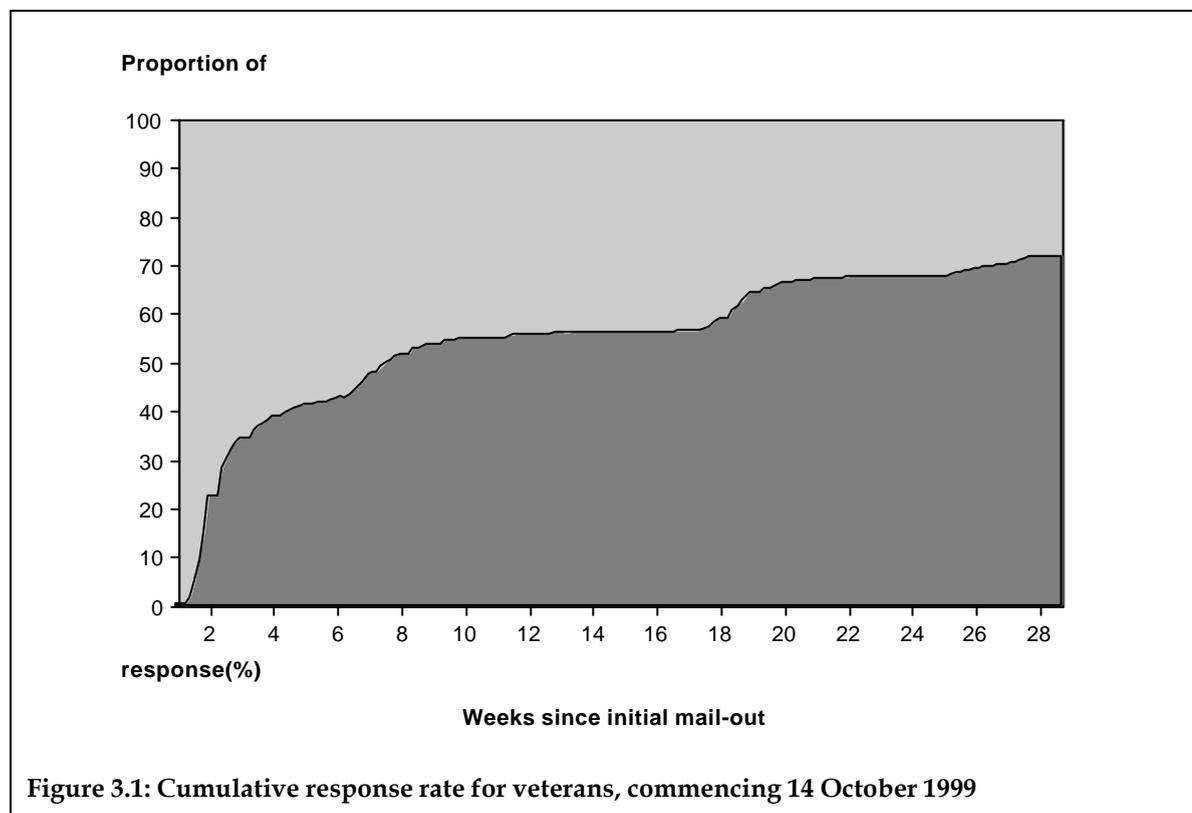
The initial mail-out of survey forms to veterans in October 1998 resulted in a response rate of 41%, which was below that needed to produce statistically reliable estimates for all conditions. Consequently, two reminder mail-outs were conducted on 23 November 1998 (Week 7) and 9 February 1999 (Week 18). These mail-outs proved successful, lifting the response rates to acceptable levels for each condition, with the exception of multiple sclerosis and motor neurone disease. To increase the response rate for these two conditions, telephone calls were made over the period 16–26 February (Weeks 19 and 20) to those veterans who had reported these conditions, but who had not responded to the Validation Study. This follow-up also proved successful, and the final response rate was 72% for all conditions combined. Within this overall response there was some variation across conditions ranging from 58% for motor neurone disease to 84% for 'other cancers'. (Table 3.1).

Figure 3.1 shows the cumulative response rate of the veterans for the return of their own forms and those for their children. The two significant increases in the response rate represent the effects of the reminder letter (Week 7) and reminder mail-out (Week 18) followed by telephone prompting (Weeks 19 and 20). The return of forms from the veterans reached a plateau in the middle of May 1999 (Week 27) at 72%, 6 months after the initial mail-out. At this time, it was thought by the Study Advisory Committee that the follow-up methods had been exhausted and the response rate was acceptable.

**Table 3.1: Response rate for veterans' specific conditions**

<b>Condition</b>	<b>Number of conditions reported in Morbidity Study<sup>(a)</sup></b>	<b>Number of responses received</b>	<b>Response rate (%)</b>
Head and neck cancer	830	593	71.4
Lung cancer	121	79	65.3
Cancer of the colon	460	344	74.8
Soft tissue sarcoma	379	269	71.0
Melanoma	2,618	1,875	71.6
Cancer of the prostate	422	316	74.9
Male breast cancer	49	34	69.4
Cancer of the testis	148	104	70.3
Cancer of the eye	95	63	66.3
Non-Hodgkin's lymphoma	130	99	76.2
All leukaemia	67	48	71.6
Other cancers	118	99	83.9
Motor neurone disease	125	72	57.6
Multiple sclerosis	82	56	68.3
<b>Total</b>	<b>5,644</b>	<b>4,051</b>	<b>71.8</b>

(a) The number of conditions reported here are derived from the electronic version of the Morbidity Study and some vary from the published results.



**Figure 3.1: Cumulative response rate for veterans, commencing 14 October 1999**

### 3.1.2 Children's conditions

To obtain satisfactory response rates for each of the children's conditions, responses from both the veterans and their children (for those aged 17 and over) were required. For children aged 17 and over, initial consent was required from the veteran to approach his child, and then the consent of the child was needed before validation could proceed. For children under age 17, or under custodial arrangements, only the consent of the veteran was required.

Table 3.2 shows the response rates obtained for each of the children's conditions. The total number of responses against each condition includes both responses by veterans for their children under 17, and the responses of veterans' children who are over 17. The total response rate for children's conditions reported in the Morbidity Study is 70.1%.

**Table 3.2: Response rate for veterans' children's conditions**

<b>Condition</b>	<b>No. of conditions reported in Morbidity Study<sup>(a)</sup></b>	<b>Total no. of responses</b>	<b>Response rate (%)</b>
Leukaemia	78	48	61.5
Wilm's tumour	48	26	54.2
Cancer of the nervous system	121	69	57.0
Other cancer	732	628	85.8
Spina bifida	442	297	67.2
Down syndrome	145	100	69.0
Tracheo-oesophageal fistula	131	87	66.4
Anencephaly	53	41	77.4
Cleft lip/palate	308	194	63.0
Absent body part	395	273	69.1
Extra body part	355	226	63.7
Died due to accident/other	920	521	56.6
Died due to illness	901	599	66.5
Died from suicide	250	156	62.4
<b>Total</b>	<b>4,879</b>	<b>3265</b>	<b>66.9</b>

(a) The number of conditions reported here are derived from the electronic version of the Morbidity Study and some vary from the published results.

As discussed in Chapter 2, four follow-up procedures were conducted to raise the response rate for children's conditions to acceptable levels. The two reminder mail-outs sent to veterans in November 1998 and February 1999 successfully raised the veteran response rate to children's conditions. The initial response rate from children aged 17 and over was below expectations, with less than 50% responding. However, two rounds of telephone follow-up procedures raised these children's response rate to almost 85%. The overall response rates for conditions ranged between 54% and 86% (Table 3.2) and were considered satisfactory for validation purposes.

### 3.1.3 Doctors' response

Having conducted a number of follow-up procedures to successfully raise the response rates to acceptable levels for veterans' and children's conditions, it was essential that the validation study receive the support of doctors.

The initial response from doctors was below expectations with only 45% of doctors returning validation forms by the due date. To improve this response, two follow-up procedures were implemented. Firstly, reminder validation forms were sent to those doctors who had not responded. Telephone prompting was then directed at those doctors who had not responded to the reminder mail-out. Both of these follow-up procedures proved highly successful in lifting the response rate from doctors to more than 85%.

Figure 3.2 shows the cumulative response rate for the doctors, for both veteran conditions and children of veteran conditions. Doctors were initially slow in responding, but responded well to the reminder mail-out and telephone prompting.

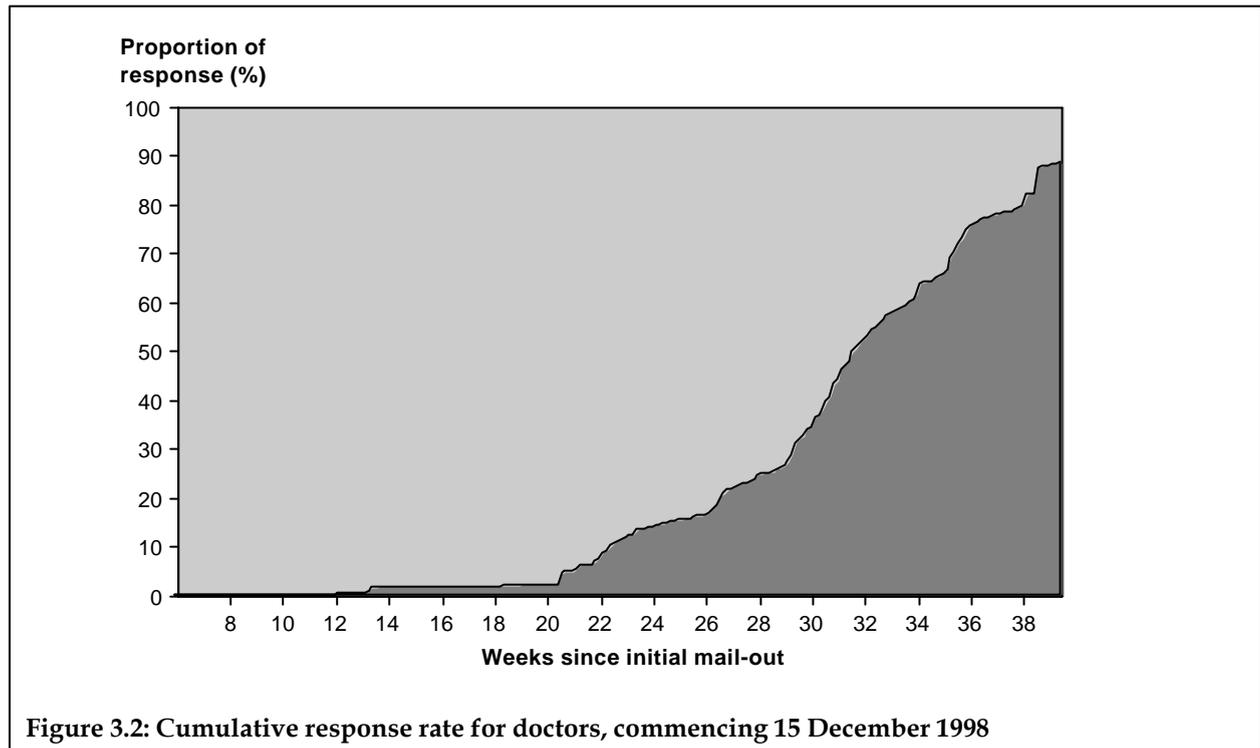


Figure 3.2: Cumulative response rate for doctors, commencing 15 December 1998

## 3.2 Validation of conditions

### 3.2.1 Veterans' conditions

The purpose of the Validation Study was to determine how many of the selected conditions identified in the Morbidity Study are valid. It is inappropriate to count only the number of valid responses to the Validation Study survey as it does not take into account the responses that were not able to be validated, among which it is expected that some valid conditions will exist. Therefore, an adjustment has been made to account for this issue in Table 3.3, and is referred to in the table as the estimated validated number of conditions. The method of adjustment is as described in section 2.3.5.

By adjusting the number of validated conditions, the estimated validated number can then be compared more confidently with the expected number of conditions based on the Australian community standard as derived in the Morbidity Study to assess whether each condition has a higher prevalence among Vietnam veterans than among the general community.

The expected number of conditions, based on the Australian community standard, includes a 95% confidence interval. For the estimated prevalence of a condition for Vietnam veterans to be considered significantly higher or lower than that for the Australian population at the 95% confidence level, the estimated prevalence should be outside the bounds of the confidence interval. The expected number of conditions based on the Australian community standard is as specified in the Morbidity Study report.

In the Morbidity Study there were no community comparisons provided for cancers of the head and neck, other cancers and total cancers. This is due to lack of compatibility between the survey question and the community comparison data (i.e. cancer registries), therefore no community comparison is possible for these groupings. In tables, a dash indicates that no community comparison is available.

A comparison of the validation estimate with the expected number of conditions, based on the Australian community standard for each condition, shows that:

- melanoma and prostate cancer have a significantly higher prevalence among the veteran population;
- colorectal cancer, lung cancer, soft tissue sarcoma, and testis cancer have a significantly lower prevalence among the veteran population; and
- all other cancers exhibit no significant difference in prevalence between the veteran population and that expected using the Australian community standard.

**Table 3.3: Number of conditions reported by veterans by validation status<sup>(a)</sup>**

Condition	No. of conditions validated	No. of conditions not validated	No. of conditions not able to be validated	No. of conditions with no response	No. of estimated validated conditions	Expected no. of conditions (confidence interval)
Head and neck cancer	132	367	107	231	160	—
Lung cancer	44	40	4	34	46	65 (49–81)
Colorectal cancer	182	160	12	107	188	221 (191–251)
Soft tissue sarcoma	10	190	71	110	14	27 (17–37)
Melanoma	423	1,241	236	732	483	380 (342–418)
Cancer of the prostate	201	105	17	101	212	147 (123–171)
Male breast cancer	2	26	6	15	2	3 (0–6)
Cancer of the testis	59	37	0	41	59	110 (89–139)
Cancer of the eye	13	41	9	32	15	11 (4–18)
Non-Hodgkin's lymphoma	57	40	9	30	62	48 (34–62)
Leukaemia	25	22	3	19	27	26 (16–36)
Other cancers <sup>(b)</sup>	48	35	6	19	51	—
<b>Total cancers</b>	<b>1,197</b>	<b>2,306</b>	<b>483</b>	<b>1,471</b>	<b>1,362</b>	<b>—</b>

(a) Extra conditions identified in the Validation Study and not in the Morbidity Study are included in this table (Section 2.3.4). They are distributed according to their validation categories

(b) Other cancers are listed by type in Appendix 17.

## Leukaemia

Leukaemia may be classified into four types. These are acute lymphatic leukaemia (ALL), chronic lymphatic leukaemia (CLL), acute myeloid leukaemia (AML) and chronic myeloid leukaemia (CML). Table 3.4 shows the number of validated leukaemias for veterans by type. CLL is the most common type of leukaemia in veterans, a finding consistent with national incidence estimates for the age group 45 to 60 years (AIHW & AACR 1998).

**Table 3.4: Number of leukaemias validated in veterans by type**

<b>Condition</b>	<b>Validated</b>
Acute lymphatic leukaemia	0
Chronic lymphatic leukaemia	16
Acute myeloid leukaemia	2
Chronic myeloid leukaemia	1
Not stated	6
<b>Total</b>	<b>25</b>

### 3.2.2 Veterans' deaths since 1997

Of the veterans who completed the Morbidity Study, 170 have since died. A full analysis of the causes of death is not possible, as ABS-coded cause of death information is not yet available for 1998 and 1999. Coded cause of death information is currently available only for 69 of the 170 veterans. Notification of death has been provided by doctors validating veterans' conditions, widows or other relatives or friends and the NDI. Causes of death for the 69 veterans, where they are available, are shown in Table 3.5.

From this table it can be seen that the majority of these deaths are due to cancers. These cancers have been included in the study as validated conditions if the validation source provided the cause of death. Lung cancer is the most common cause of death in this subset of veterans, followed by heart disease. This is not surprising as lung cancer has the highest rate of mortality of cancers and heart disease has the highest death rate for males in the 45–60 year age group (Dunn et al. (forthcoming)).

**Table 3.5: Number of veterans' deaths since completing the Morbidity Study, by cause**

<b>Cause of death</b>	<b>No. of deaths</b>
Cancer of the brain	2
Cancer of the colon	5
Cancer of the head and neck	2
Cancer of the lung	12
Cancer of the prostate	5
Cancer of the rectum	3
Other cancers	18
Cerebrovascular disease	2
Heart and circulatory system disease	8
Motor neurone disease	2
Multiple sclerosis	1
Other illnesses	9
<b>Total</b>	<b>69</b>

It is important to note that two of the veterans have died from motor neurone disease. The expected number of this condition, based on the community comparison in the Morbidity Study, is two. It seems likely that further data collected about this condition may find an excess of the condition in Vietnam veterans.

### 3.2.3 Children's conditions

Validation results for each of the children's conditions are provided in Table 3.6. As with the veterans' conditions, the estimated validated number of conditions includes an adjustment for responses that were not able to be validated.

'Extra body part' is the only children's condition that does not have a corresponding community comparison and therefore no assessment can be made of the significance of this result.

Comparisons of the estimated number of validated conditions among the children of Vietnam veterans with the expected number, based on the Australian community standard, show:

- the number of spina bifida and cleft lip/palate conditions are significantly higher than expected;
- the number of conditions relating to Wilm's tumour, Down syndrome, tracheo-oesophageal fistula, absent body parts, anencephaly and the combination of other congenital malformations exhibits no significant differences from the expected numbers of conditions; and
- the number of conditions related to cancer of the nervous system, leukaemia and a combination of all other cancers is significantly lower than expected.

**Table 3.6: Number of veterans' children's conditions by validation status<sup>(a)</sup>**

Condition	No. of conditions validated	No. of conditions not validated	No. of conditions not able to be validated	No. of conditions with no response	No. of estimated validated conditions	Expected no. of conditions (confidence interval)
Leukaemia	30	13	13	29	39	57 (42–72)
Wilm's tumour	7	15	8	22	10	7 (2–12)
Cancer of the nervous system	26	44	13	52	31	48 (34–62)
Other cancer <sup>(b)</sup>	101	309	84	266	122	333 (297–369)
Total cancer	164	381	118	369	200	—
Spina bifida—maxima	34	185	102	149	50	33 (22–44)
Down syndrome	49	27	28	43	67	92 (73–111)
Tracheo-oesophageal fistula	7	60	26	38	10	23 (14–32)
Anencephaly	10	27	10	11	13	16 (8–24)
Cleft lip/palate	57	63	77	107	94	64 (48–80)
Absent external body part	14	166	105	110	22	34 (23–45)
Extra body part <sup>(c)</sup>	38	97	129	119	74	—

(a) Extra conditions identified in the Validation Study and not in the Morbidity Study are included in this table (section 2.3.4). They are distributed according to their validation categories.

(b) Other cancers are listed by type in Appendix 18.

(c) Extra body parts are listed by type in Appendix 19.

### Leukaemia

As with the veterans, the validated leukaemias of the veterans' children were also divided into the four types of leukaemia. These are shown in Table 3.7 which shows that ALL is the most common type of leukaemia in the veterans' children. This is consistent with national incidence patterns for children up to the age of 20, after this age, AML becomes

more common (AIHW & AACR 1998). These trends are reflected in the results as the veterans' children range in age from young children to the 30–35 year age group.

**Table 3.7: Number of leukaemias validated in veterans' children by type**

Condition	Validated
Acute lymphatic leukaemia	14
Chronic lymphatic leukaemia	1
Acute myeloid leukaemia	4
Chronic myeloid leukaemia	1
Not stated	8
<b>Total</b>	<b>28</b>

### 3.2.4 Children's deaths

In the Morbidity Study, veterans reported on deaths in their children according to three categories of cause:

- accident/other
- illness
- suicide.

The Morbidity Study showed reported children's death rates above those expected based on Australian community standards in all three categories. In the validation of these reported deaths, it was found that a number of children's deaths reported in the Morbidity Study as deaths due to 'accident/other' were actually deaths due to illness. For example, deaths resulting from SIDS and various congenital anomalies were in many cases classified as 'accident/other', whereas the Australian community standard allocates these deaths to the illness category. Table 3.8 shows the results of this reclassification.

**Table 3.8: Number of deaths in veterans' children – corrected for cause of death**

Condition	Responses by cause of death reported in Morbidity Study	Responses after reclassifying to the correct cause of death
Died due to accident/other	893	790
Died due to illness	898	1,006
Died from suicide	243	238
<b>Total</b>	<b>2,034</b>	<b>2,034</b>

Validation of the children's deaths confirmed the findings from the Morbidity Study. The number of deaths for veterans' children was higher than expected, based on the Australian community standard for all three causes of death (Table 3.9).

**Table 3.9: Number of veterans' children's deaths by validation status**

Condition	Validated	Not validated	Not able to be validated	Estimated validated	Expected validated (confidence interval)
Died due to accident/other	219	43	528	660	365 (328–402)
Died due to illness	504	33	469	944	805 (749–861)
Died from suicide	111	4	123	230	75 (58–92)
<b>Total</b>	<b>834</b>	<b>80</b>	<b>1,120</b>	<b>1,834</b>	—

Suicide shows the most substantial difference, with the number of veterans' children committing suicide 3 times as high as expected based on the Australian community standard. Deaths from accident/other causes were approximately 1.6 times as high as expected based on the Australian community standard, and deaths from illness were 1.1 times higher than expected.

### 3.2.5 'New conditions' and 'new veterans'

As mentioned in Chapter 2, 'new conditions' refer to those conditions reported by veterans to have occurred between the Morbidity Study and the Validation Study. New veterans are those who did not participate in the Morbidity Study, but sought to participate in the Validation Study. The conditions reported by new veterans and their children, and those diagnosed after the Morbidity Study in 1997, were not included in the results above as they would have introduced a selection bias. Instead, their conditions are provided in the following tables, for veterans and their children respectively.

Melanoma of the skin, cancer of the colon and cancer of the head and neck are the most common conditions reported by veterans to have occurred since the Morbidity Study. New veterans have reported a range of the different cancers, most of which have fallen in the 'other cancers' category (Table 3.10). Since the Morbidity Study, the most common conditions in the veterans' children are deaths due to accidents with new veterans reporting deaths from accident and suicides in their children (Table 3.11).

**Table 3.10: New conditions and new veterans**

<b>Condition</b>	<b>No. of new conditions<sup>(a)</sup> validated</b>	<b>No. of new conditions<sup>(a)</sup> not validated and not yet validated</b>	<b>No. of conditions of new veterans<sup>(b)</sup> validated</b>	<b>No. of new conditions of new veterans<sup>(b)</sup> not validated and not yet validated</b>
Head and neck cancer	2	6	0	0
Lung cancer	0	1	0	0
Cancer of the colon	3	0	3	0
Soft tissue sarcoma	0	1	0	0
Melanoma	6	8	1	1
Cancer of the prostate	0	2	0	0
Male breast cancer	0	0	0	0
Cancer of the testis	0	0	0	0
Cancer of the eye	0	0	0	0
Non-Hodgkin's lymphoma	0	2	0	1
Leukaemia	1	1	0	0
Other cancers	4	2	3	2
Motor neurone disease	0	1	0	5
Multiple sclerosis	0	1	0	6
<b>Total</b>	<b>16</b>	<b>25</b>	<b>7</b>	<b>11</b>

(a) Condition relates to a veteran included in the Morbidity Study, but diagnosed after the Morbidity Study.

(b) Condition relates to a veteran not participating in the Morbidity Study.

**Table 3.11: Number of conditions in children – new conditions and new veterans**

<b>Condition</b>	<b>No. of new conditions<sup>(a)</sup> validated</b>	<b>No. of new condition<sup>(a)</sup> not validated and not yet validated</b>	<b>No. of conditions of new veteran<sup>(b)</sup> validated</b>	<b>No. of conditions of new veteran<sup>(b)</sup> not validated and not yet validated</b>
Leukaemia	1	0	2	1
Wilm's tumour	0	0	0	0
Cancer of the nervous system	1	0	0	1
Other cancer	1	3	1	0
Total cancer	0	6	0	5
Spina bifida—maxima	4	4	2	1
Down syndrome	0	0	1	0
Tracheo-oesophageal fistula	0	0	0	0
Anencephaly	0	0	0	0
Cleft lip/palate	0	0	1	0
Absent body part	1	1	0	0
Extra body part	0	2	0	2
Died due to accident/other	2	3	2	20
Died due to illness	7	21	3	13
Died from suicide	1	0	0	7
<b>Total</b>	<b>18</b>	<b>40</b>	<b>12</b>	<b>50</b>

(a) Condition relates to a child of a veteran included in the Morbidity Study, but diagnosed after the Morbidity Study.

(b) Condition relates to a child of a veteran not participating in the Morbidity Study.

# 4 Discussion, conclusions and recommendations

The results in Chapter 3 indicate some noteworthy and concerning patterns in conditions affecting both veterans and their children. Taken as a whole this evidence suggests that the veteran community and their children have some significant health problems related to the chronic conditions and particular causes of death followed-up in this study. However, these results reflect the final product of a complex follow-up process reliant on veterans, their children, validating sources and a series of key assumptions. It is therefore appropriate to establish a level of confidence in these results, so that any application of them can be undertaken in an informed manner. Therefore this chapter will focus on the reliability of these estimates by discussing and testing the relative strengths and weaknesses of the validation process and discuss the conclusions that might be drawn from the results and their implications. Finally, the chapter will propose some recommendations for further action in relation to the study findings.

This study relies on several key components:

- the Morbidity Study and its estimates of Australian community standards
- the responses from veterans, their children and validation sources
- the techniques used to validate the conditions
- assumptions about conditions not able to be validated.

The following sections set out the relative strengths and weaknesses in relation to each of these components and assess their likely impact on the final results.

## 4.1 The Morbidity Study

### 4.1.1 Data from the Morbidity Study

The basis for the Validation Study work are the claims made by veterans regarding conditions in themselves and their children in the Morbidity Study. Therefore, reliance on these data is critical in the process. An assessment of the electronic records provided from the Morbidity Study indicated that, for the most part, the Morbidity Study data were of a reasonable standard. Its accuracy in relation to names and addresses was consistently of good quality which ensured that the Validation Study surveys were delivered appropriately to veterans. In the period between the studies some veterans had changed addresses; this issue was overcome effectively by the use of alternative sources of information.

In assessing the electronic records relating to conditions in the Morbidity Study, some problems were found either by the Institute's quality appraisal or as a result of feedback from respondents. Some of these problems and their impacts are:

- Misclassification of conditions e.g. Hodgkin's disease to non-Hodgkin's lymphoma, or congenital malformations being misallocated in the 'cause of death' groupings. These conditions have been reclassified in the Validation Study where veterans or validation sources have indicated. Where no response has been provided no reallocation is possible.
- Some suspected double counting of children's conditions was identified in the data set. Most of these were able to be resolved as a result of the Validation Study processes, e.g. survey or telephone follow-up.
- The published Morbidity Study data underestimate the number of conditions in some tables due to a grouping of data. Often this undercount was relatively small. However, the largest difference was for spina bifida (379 in the Morbidity Study and 442 in the Validation Study). Therefore the electronic data set was used in the Validation Study as it recorded the actual value.
- A small number of incorrect conditions was attributed to veterans or their children due to data errors.
- The confidence interval in the Morbidity Study report for veterans' lung cancer was incorrect and should be 49-81, not 41-89 as reported.

In summary, the Morbidity Study data did contain some quality problems, most of which were addressed by the design of the Validation Study surveys.

#### **4.1.2 Community standards**

The community standards used for comparison with the validated responses were derived in the Morbidity Study. In conducting the Validation Study the AIHW was advised by the Study Advisory Committee to proceed with these already accepted and published standards. The AIHW has accepted this advice, and is satisfied that the models as described and data sources used give a reasonably reliable estimate of prevalence, but warns that the interpretation of the results in the Validation Study are dependent of the validity of these community standards.

A new community standard was required for the colorectal cancer category and the AIHW was asked to derive it. The AIHW was unable to obtain the exact derivations of these community standards and the methods were not adequately described in the Morbidity Study to enable reproduction. A prevalence modelling program was used, which incorporates the known incidence, survival and mortality distributions. A description of this method is provided in Appendix 16. This model was cross checked using the published estimates for colon cancer and there was only a small variation. The method was then used to create the colorectal cancer community standard.

## **4.2 Responses from veterans, their children and validation sources**

While the patterns of response to the Validation Study survey were generally satisfactory, there were some demographic variations in the level of response. There was also some variation in the validation method by condition and the date of diagnosis of conditions. This section explores these variations to assess whether they are likely to affect the interpretation of the results in Chapter 3.

## 4.2.1 Veterans

An examination of the response rates in veterans by State and Territory indicated no statistically significant variation. The highest rate was in the Australian Capital Territory at 77% and the lowest was in the Northern Territory at 66%, a national average of 68%.

Over 80% of veterans involved in the Validation Study are aged 45–64, with the largest group aged 50–54. There were some small variations (under 10%) in the response rates of these veterans by age group. However, response rates from those aged between 50 and 84 were above 65%. The oldest (aged 85 and above) and youngest veterans (less than 50) had the lowest response rates (approximately 60%), although they accounted for only 3 % of the expected responses.

The distribution of responses within validation categories indicates that the NCSCH is the dominant validation source accounting for 68% of each of the validated and not validated conditions (Table 4.1). Clinicians also play an important role validating 21% of conditions and not validating 16%. Of interest in this table are the reasons for not being able to validate a condition. These reasons are spread evenly between veterans not providing enough information for contacting clinicians, clinicians having insufficient information to make a decision or not responding, and insufficient information to link to the NCSCH. It is likely that conditions that are not able to be validated would be spread between being validated and not validated if further work had been possible to seek alternative validation sources, or to further prompt the known validation sources. The exact distribution is not known. An analysis of the distribution assumption used in Chapter 3 is presented in a later section.

**Table 4.1: Percentage of responses by validation outcome and source**

<b>Validation source</b>	<b>Validated</b>	<b>Not validated</b>	<b>Not able to be validated</b>
Clinician	21	16	20
No clinician response	—	—	22
Documentation or DVA claims	10	7	—
NCSCH	68	68	24
Veteran response	—	9	34
NDI	1	—	—
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>

Regardless of the validation sources, the distribution of responses across the validation options was similar for the validated category (Table 4.2). However, there was some variation between the validation sources in the not validated and not able to be validated categories. It appears that many doctors validated a higher proportion of the conditions in the not able to be validated category, whereas the decision making process (record linkage) in the NCSCH was more definitive and either ruled the condition validated or not. The only conditions not able to be validated in the NCSCH occurred where diagnosis year or State/Territory of diagnosis was not provided by the veteran.

One of the concerns in this study when dealing with cancer diagnoses was the confusion of non-melanocytic skin cancers (NMSC) with melanoma by veterans. NMSC registrations are not collected by cancer registries. Given the large number of melanomas reported in the study, they have a significant impact on the over-distribution of responses across the validation options. When this effect is removed it is apparent (Table 4.2) that there is a significant improvement in the validated category at the expense of the not validated category for both the NCSCH and clinicians. That is, there appears to be no significant

differential in validation of conditions including or excluding melanomas. A closer examination of the differentials by individual conditions shows little variation between sources.

**Table 4.2: Percentage of responses by source and validation outcome**

Validation source	Validated	Not validated	Not able to be validated	Total
Clinician	35	51	14	100
NCSCH	33	62	5	100
Clinician (excluding melanoma)	43	42	15	100
NCSCH (excluding melanoma)	41	54	5	100

An analysis was conducted to ascertain whether the year of diagnosis and the likelihood of validation had any particular bias. Not surprisingly, it was found that where veterans did not indicate the year of diagnosis there was a higher propensity to find them not validated, regardless of validation source. Diagnoses made in veterans in the 1960s through to the 1980s showed little variation in the validation rates observed (approximately 25%), but this increased to 35% for those diagnosed in the 1990s. The proportion of conditions not validated increased in the 1980s and 1990s possibly at the expense of the conditions not able to be validated, which showed a decrease over the same period. This is probably the greater impact of the NCSCH in the validation process, where conditions were more likely to be not validated than not able to be validated.

This analysis suggests that some underestimation of cancers diagnosed in the 1960s through to the 1980s is a possibility. This underestimation may be in the order of 10%. Therefore, it may be prudent to use the estimates in the results tables as a minimum level, with some likelihood of further cancers not able to be validated due to an inability to retrieve appropriate clinical records from this period.

## 4.2.2 Deaths in veterans

There were 170 veterans who were known to have died between the Morbidity Study and the Validation Study. The number of veterans who have died in this time may be higher. If the death was not reported to the Validation Study, or registered on the death index yet, these deaths could not be validated. From the 170 deaths reported, it was possible to extract a coded cause of death for 69 of these from currently available data sources – the remainder will not be available until after this study is completed. Where the cause of death was available, it was used to validate conditions amongst veterans if the cause of death related to the condition reported by the veteran. Where this was not the case and no further information was available to validate the condition(s), the veteran was treated as a non-respondent.

An assessment was made of these non-respondents (101 veterans) and their conditions, and their likely impact on the number of estimated validated conditions. If it was assumed that all conditions were validated in these veterans then the number of estimated validated conditions would rise. However, the impact would not be such that it would increase this estimate to a level above the expected range (making it statistically significant). For all condition types it would align the currently lower than expected number of conditions in veterans with the expected level. For example, 17 veterans whose cause of death is unknown earlier reported that they had lung cancer. If all 17 conditions

are assumed to be validated, the estimated number of validated conditions would increase from 44 to 61 and this is within the expected 95% confidence interval range of 49 to 81.

### 4.2.3. Veterans' children

Information received about the children in the Validation Study indicated that the sex distribution of children with the selected conditions was slightly skewed towards males. All the cancers and the deaths were higher in males, whereas most of the congenital anomalies were higher in the females.

The response rates from veterans' children aged over 17 also indicated no statistically significant variation between the States and Territories, with the highest rate in Tasmania at 100% and the lowest in South Australia at 76%, with an average of 85%.

Eighty-three per cent of the veterans' children aged over 17 are in their twenties, with the largest group aged 25–29. The youngest group (15–19 years) and the oldest (30–39 years) have the highest response rates (88% and 90% respectively), with the children in their twenties being slightly lower (84%).

The distribution of responses for the veterans' children's conditions indicates that the clinician is the dominant validation source for those that were validated, whereas the veterans' response is the dominant validation source for those conditions not validated. This is where veterans confidently stated their child did not have a condition attributed to them in the Morbidity Study. The NCSCCH has a smaller role in the validation of veterans' children because cancers are only a small proportion of the conditions being validated. The distribution of the not able to be validated is spread fairly evenly with the main reason for not being able to validate a lack of response from the veterans' child. Twenty-two per cent of the not validated conditions were a result of the adjustment made from those who reported conditions in the Morbidity Study, but not in the Validation Study, and were unable to be contacted (section 2.3.5).

**Table 4.3: Percentage of responses by validation outcome and source**

<b>Validation source</b>	<b>Validated</b>	<b>Not validated</b>	<b>Not able to be validated</b>
Clinician	63	16	12
No clinician response	—	—	15
Documentation	11	1	—
NCSCCH	18	8	—
Veteran response	—	55	26
NDI	7	1	—
CMR	7	1	—
No response from child	—	—	37
Adjustments due to specific non-response	—	22	10
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>

An analysis, similar to that for the veterans, was conducted to ascertain whether the year of diagnosis and the likelihood of validation had any particular bias. It was found, not surprisingly, that where veterans' children did not indicate the year of diagnosis there was a higher propensity to find them not validated, regardless of the validation source. Unlike the veterans, there appeared to be a greater similarity between diagnosis years (grouped

into 5-year blocks) and the rate of validation. There was slightly more variation in the proportions not able to be validated, but of little significance.

This analysis tends to indicate that the diagnostic records of veterans' children used for validation are more consistently available than in the veterans across the period of analysis.

## **4.3 Validation by sources/technique**

### **4.3.1 The record linkage process**

The Validation Study relies heavily on record linkages between the NCSCH, the NDI and the CMR and the veterans' and children's records. Over 65% of validated responses have been derived through this process. It is therefore important to discuss the technique and its application and any impact it may have on the results.

The linkage process is a probabilistic one. This is because not every veteran or veteran's child can be uniquely identified. Identification of individuals by name, date of birth, sex and some details about the condition (e.g. date of diagnosis or death) across separate databases brings with it some risk of incorrectly matching two individuals together (false positives), or not linking the same individual (false negative). This occurs as a result of incorrect details in the databases for the same individual (e.g. birth dates) and also when there is more than one individual with similar characteristics.

The automated record linkage system used in the Validation Study is Automatch. This system is able to allocate a weight to a matched pair which is an indicator of match strength—based on a comparison of names, transpositions of name components, phonetic and common variants of name components, dates of birth and minor variations of these dates. It also takes account of the frequency with which these characteristics occur in the population, e.g. Smith (common name) or Lexcen (uncommon). This weight and the matched pair are also subject to a clerical case by case review before being accepted as a correct match.

In undertaking the record linkage process, as much information as was available was used to ensure that the match was correct. Unfortunately, this was made more difficult because the data file for the veterans contained mostly initials for the given names, not full names. This increased the risk of false positive matches (e.g. John Smith and Joe Smith would be equivalent as J Smith). Also, the risk of false negative matches was increased as possible matches were discarded because not enough information was provided to accept the match. Some of this risk was offset through an automated or clerical review of other information concerning the veteran, e.g. data of birth or address information. However, the review process took a conservative approach, only accepting matches that were of good quality.

### **4.3.2 NCSCH and State and Territory cancer registries**

#### **Data quality and limitations**

Cancer registry data are collected under State and Territory legislation, and therefore have excellent coverage compared with other health data collections. Coverage in the 1990s is estimated to be between 95% and 98% of new cases. Legislation has been in effect since 1982 in most jurisdictions with registrations prior to this occurring on a voluntary basis. In the Australian Capital Territory the cancer registry only became operational from 1994.

This may have the effect of under-counting cancers diagnosed in the Australian Capital Territory prior to 1994 and is known to have affected the registration of melanoma in the Australian Capital Territory. Also, melanoma was known to be under counted in New South Wales for the period 1972–1988, due to poor registration of this cancer through pathology laboratories. Data collection in the Northern Territory was also known to be poor in the 1980s across all cancer sites. To compensate for the lack of coverage, any cancers that were diagnosed before 1982 and after 1996 were also sent to a clinician in the Validation Study.

In order to test the sensitivity of the linkage process a set of 105 cancers that had been confirmed by clinicians (between 1982 and 1996) were also linked to the NCSCH – 53% of these cancers were found on the NCSCH.

Of the cancers not on the NCSCH, 55 were reported by veterans and their clinicians as melanoma of the skin and cancers of the head and neck. In this study it has been shown that a substantial proportion of reported head and neck cancers are in fact cancers of the skin. For the purposes of this analysis these cancers will be treated as melanoma. These types of cancers have two specific problems that make their identification on the NCSCH problematic. It is possible that a proportion of these cancers may not have been found to be melanomas on histological examination, but non-melanocytic skin cancer, and therefore are not reported to the NCSCH. It is also possible that clinicians removed the skin lesions (melanoma or non-melanocytic skin cancer) without sending the excised tissue for histological examination. Therefore, a melanoma diagnosis would not be registered on the NCSCH. In both scenarios, the clinician’s notes may have indicated melanoma or suspected melanoma. These scenarios would account for some underestimation in the record linkage process. By removing the impact of the melanomas in the linkage assessment, then the concordance between the clinician validation and validation using the NCSCH increases to 62%.

**Table 4.4: Quality assessment of the record linkage process**

<b>Cancer sites</b>	<b>Found</b>	<b>Not found</b>	<b>Total</b>
Melanomas and cancers of the head and neck	25	30	55
All other cancers	31	19	50
<b>Total</b>	<b>56</b>	<b>49</b>	<b>105</b>

In appraising the impact of this concordance level on the validation results, three key issues need to be considered;

- whether the cancers were not found due to the record linkage process;
- whether the cancers were not found on the NCSCH as they were never registered;
- whether the cancers reported by the veteran/clinician were in the time period corresponding with the NCSCH

In the sample of 105 cancer cases, 49 cancers were not found (Table 4.4). In an intensive assessment of these missed cancers, it was found that

- 8% failed as a result of the record linkage process (due mainly to a lack of complete date of birth information);
- 67% were never registered by the State and Territory cancer registries and therefore were not available to the NCSCH; and
- 25% were found to be registered in 1997 by the cancer registries, not 1996 as reported by the veterans/clinicians. Currently, 1997 data is not available on the NCSCH.

If the last two factors are removed from an assessment of the record linkage process alone then the concordance between the two validation sources improves substantially from 53% to 93%.

However, it is important to note that two thirds of the sample were not registered by the cancer registries, and therefore were not included in the generation of the community comparison. This is because the Morbidity Study community comparison was based on the NCSCH data. This situation eliminates the impact of these missed cancers for the purposes of significance testing. However, if for other purposes the exact number of cancer cases needs to be known, then the number of estimated validated cancer conditions in Tables 3.3 and 3.6 would need to be increased by up to 30%. This would need to be assessed on a site by site basis as the concordance rate shows some variation.

Similar techniques to those described above were used when matching deaths in veterans or their children to the NDI, but here more accuracy would be achieved on such a well-defined event.

### **4.3.3 Registrars of Births, Deaths and Marriages and the National Death Index**

#### **Data quality and limitations**

Deaths are registered in each State and Territory under legislation that has operated since the beginning of the century. Australia has a good death data collection system when compared internationally, particularly when a cause of death (such as suicide) is used as an index of quality.

All deaths occurring since 1980 have been electronically registered and transferred to the NDI. Areas of concern in death registration relate mainly to the data collection process that relies on information provided by the next of kin. Often this information can be inexact due to the emotional circumstances under which it is provided. This often translates into variations between official names and names by which the person is known, estimated birth dates, or missing or poorly transcribed information. Occasionally deaths may be missed due to the transfer problems between coronial inquests, the standard registration system and the NDI. The quality of information has also changed over time, with dates of birth being recorded in all jurisdictions after 1995. Prior to this date, only three jurisdictions recorded this information and other jurisdictions used age at death from which an approximated year of birth could be calculated.

Cause-of-death information depends on the information provided by the certifying clinician on the death certificate. Until 1997, only a single underlying cause of death had been used to report cause of death on the NDI, despite other related causes of death being recorded on the death certificate (multiple causes of death). The effect of this may be that some causes of death reported in the Morbidity Study by veterans may not be reflected in the cause-of-death data. This leads to an underestimation of the numbers of deaths allocated to a particular cause. The underestimation is somewhat offset by the breadth of the categories used in the Morbidity Study which tends to aggregate a range of deaths, e.g. all cardiovascular-related causes of death are included in the illness category. There is anecdotal evidence to suggest an under-reporting of suicide and other causes of death (e.g. accidental drug overdose, HIV/AIDS) due to the social stigma and financial implications surrounding such a finding.

## 4.3.4 Clinicians

### Data quality and limitations

Clinical records held in institutions are usually active for only 7 years and after this some institutions destroy or archive records. This policy restricts the quantity of information about patients in research studies as institutions are loath to retrieve information older than this for non-clinical applications. This will have had an impact on the number of validations of conditions amongst veterans and their children, and particularly affect diagnoses prior to 1990.

Difficulties relating to clinical records are also encountered when dealing with general practitioners and specialists. Many of these clinicians will have retired, merged or sold their practice, or died. In many of these situations, patient records are often destroyed and follow-up is reliant on the current clinician having a complete patient history. This process also relies on the veteran or their child having provided the most appropriate clinician for the validation of their condition. In many instances, the clinician details provided by the veteran or their child were no longer appropriate and therefore no validation could be undertaken. No further clinician details were pursued with the veteran if their first option was unable to be contacted.

One advantage in pursuing medical records for this cohort was that the DVA and Central Army Records Office (CARO) also held medical history records. In other cohort follow-up studies, such comprehensive data collections under the control of key and sympathetic organisations are normally unavailable. These data sources proved important in validating older information about veterans, where CARO was the nominated validation source.

## 4.4 Non-respondents and ‘not able to be validated’ responses

As stated in section 2.3.5, responses from veterans and their children were divided into three categories: validated, not validated and not able to be validated. However, there was also a substantial number of veterans and their children who did not respond to the survey. Section 2.3.5 set out methods which redistributed, to validated and not validated categories, these non-respondents and those whose condition could not be validated due to incomplete information or a non response from the validating clinician. This redistribution was done by prorating the non-respondents between the validated and not validated categories.

In order to test the impact of the assumptions behind these methods five variations were examined, with the outcome compared with the Morbidity Study derived community standard.

Five models were tested which combined various response components in order to determine the final estimated validated response. These components are:

- (a) Counting only positively validated responses
- (b) The validated component of those responses not able to be validated due to a non-response from the clinician or a clinician indicating they had insufficient information to confirm the condition – prorated between the validated and not validated responses
- (c) The validated component of those responses not able to be validated regardless of reason – prorated between the validated and not validated responses

- (d) Redistributing cases from non-responding veterans between validated, not validated and not able to be validated responses.
- (e) The validated component of non-responses prorated between validated and not validated responses.
- (f) Excluding non-respondents to the Validation Study among veterans.

The five models decrease in their level of strictness for the validation of responses. The results of Model 3 were reported in Chapter 3.

The Models estimated validated conditions by:

**Model 1**

- (a) counting only positively validated responses; and
- (f) but excluding non-respondents among veterans

**Model 2**

- (a) counting positively validated responses; and
- (b) the validated component of those responses not able to be validated due to a non-response from the clinician or a clinician indicating they had insufficient information to confirm the condition—prorated between the validated and not validated responses
- (f) but excluding non-respondents among veterans

**Model 3**

- (a) counting positively validated responses; and
- (c) the validated component of those responses not able to be validated regardless of reason—prorated between the validated and not validated responses
- (f) but excluding non-respondents among veterans

**Model 4**

- a) counting positively validated responses; and
- b) the validated component of those responses not able to be validated due to a non-response from the clinician or a clinician indicating they had insufficient information to confirm the condition—prorated between the valid and not validated responses; and
- c) redistributing cases from non-responding veterans between validated, not validated and not able to be validated responses.

**Model 5**

- (a) counting positively validated responses; and
- (c) validated component of those responses not able to be validated regardless of reason—prorated between the validated and not validated responses; and
- (e) validated component of non responses prorated between validated and not validated responses.

The assumption behind component (b) is that respondents have provided information available to them for validation in a manner confident of a likely positive response. However, the information has been insufficient for the Validation Study to validate the condition through its validation sources. It is therefore assumed that these responses can be counted as validated. Component (c) takes the same assumption but does not

distinguish between the reasons for the inability to validate the condition (e.g. includes a non-response from a child follow-up although a veteran has responded).

Conditions whose estimated incidence is higher than expected from community rates when using Models 1 to 3, have a greater level of confidence associated with them than those only becoming statistically significant in Models 4 and 5, where there may be some doubt about the redistribution of the non-respondents. While it would be of great benefit to the Validation Study to have a greater response rate or further opportunity to seek alternative validation sources for those conditions not able to be validated, the redistribution of these conditions is reasonable but based on limited evidence.

The outcome of these models is summarised for veterans in Table 4.5 and for their children in Table 4.6. In both tables, the expected number of conditions and the 95% confidence intervals shown in brackets, are derived from the Morbidity Study. The results indicate that the two conditions in veterans, melanoma and prostate cancer, remain statistically significantly high regardless of the model used. However, the results for cancer of the eye, leukaemia and non-Hodgkin's lymphoma rely on the redistribution of non responses to reach statistical significance (Models 4 and 5).

**Table 4.5: Validation results in veterans using selected reallocation models and their significance level**

Condition	Model 1	Model 2	Model 3	Model 4	Model 5	Expected no. of conditions
Lung cancer	44	46	46	64	64	65 (49–81)
Colorectal cancer	182	185	188	241	245	221 (191–251)
Soft tissue sarcoma	10	13	14	37	19	27 (17–37)
Melanoma	423	460	483	678	669	380 (342–418)
Prostate cancer	201	210	212	276	279	147 (123–171)
Breast cancer	2	2	2	6	4	3 (0–6)
Testis cancer	59	63	59	71	83	110 (89–139)
Eye cancer	13	14	15	24	23	11 (4–18)
NHL	57	61	62	78	80	48 (34–62)
Leukaemia	25	26	27	35	37	26 (16–36)
Lung cancer	Low	Low	Low	—	—	
Colorectal cancer	Low	Low	Low	—	—	
Soft tissue sarcoma	Low	Low	Low	—	—	
Melanoma	High	High	High	High	High	
Prostate cancer	High	High	High	High	High	
Breast cancer	—	—	—	—	—	
Testis cancer	Low	Low	Low	Low	Low	
Eye cancer	—	—	—	High	High	
NHL	—	—	—	High	High	
Leukaemia	—	—	—	—	High	

*Notes*

1. High—The estimated validated conditions are statistically significantly higher than the Morbidity Study derived community standard at the 95% confidence level.
2. Low—The estimated validated conditions are statistically significantly lower than the Morbidity Study derived community standard at the 95% confidence level.
3. Dashes indicate no statistically significant differences from the Morbidity Study derived community standards.

Cancer of the testis remains statistically significantly low regardless of the model used, whereas cancers of the lung, colorectal cancer and soft tissue sarcoma are low for Models

1–3 after which they are aligned with the community standard based on the redistribution of non-respondents (Models 4 and 5).

The finding in the Validation Study regarding lung cancer prevalence in Vietnam veterans is at odds with those published in the *Mortality of Vietnam Veterans: The Veteran Cohort Study* (DVA 1997a) and other veteran studies. These studies show that the death rate from lung cancer plays a part in the excess mortality among Vietnam veterans (DVA 1997a). The lower than expected lung cancer prevalence in the Validation Study may reflect the severity of the disease and the high possibility that many of these veterans may be unable to respond to the Validation Study survey. This non-response may be due to the fact that the veterans suffering lung cancer are either too ill to respond, or are under care arrangements and the survey form was not transferred to them from their home address. The Validation Study has also found 17 veterans who reported lung cancer in the Morbidity Study, but have subsequently died. In these veterans, the cause of death has not yet been confirmed through the ABS death coding systems. If these lung cancers were validated, then the prevalence would be at least equivalent to the community standard. It would appear that this cancer has been under-reported to the Validation Study.

The results for the children’s conditions indicate that reallocation of some form is required for any condition to become statistically significant. Table 4.4 shows that the results for spina bifida and cleft lip/palate are statistically significant after reallocation of the not able to be validated cases (Model 3) and when the non-respondents are factored in (Models 4 and 5). The results for Wilm’s tumour becomes significant only after the redistribution of the non-respondents (Model 5).

**Table 4.6: Validation results in veterans’ children using selected reallocation models and their significance level**

Condition	Model 1	Model 2	Model 3	Model 4	Model 5	Expected no. of conditions
Leukaemia	30	30	39	46	59	57 (42–72)
Wilm’s tumour	7	7	10	13	17	7 (2–12)
Cancer of the nervous system	26	27	31	44	50	48 (34–62)
Other cancer	101	103	122	163	187	333 (297–369)
Spina bifida—maxima	34	38	50	68	73	33 (22–44)
Down syndrome	49	51	67	72	95	92 (73–111)
Tracheo-oesophageal fistula	7	8	10	13	14	23 (14–32)
Anencephaly	10	11	13	13	16	16 (8–24)
Cleft lip/palate	57	71	94	119	144	64 (48–80)
Absent external body part	14	17	22	37	31	34 (23–45)
Leukaemia	Low	Low	Low	—	—	
Wilm’s tumour	—	—	—	High	High	
Cancer of the nervous system	Low	Low	Low	—	—	
Other cancer	Low	Low	Low	Low	Low	
Spina bifida—maxima	—	—	High	High	High	
Down syndrome	Low	Low	Low	Low	—	
Tracheo-oesophageal fistula	Low	Low	Low	Low	Low	
Anencephaly	—	—	—	—	—	
Cleft lip/palate	—	—	High	High	High	
Absent external body part	Low	Low	Low	—	—	

*Notes*

1. High—The estimated validated conditions are statistically significantly higher than the Morbidity Study derived community standard at the 95% confidence level.
2. Low—The estimated validated conditions are statistically significantly lower than the Morbidity Study derived community standard at the 95% confidence level.
3. Dashes indicate no statistically significant differences from the Morbidity Study derived community standards.

Other cancers and tracheo-oesophageal fistula remain statistically significantly low and the results for leukaemia and anencephaly show no statistical significance regardless of the model used. Cancer of the nervous system and absent body parts show statistically significantly low results until the redistribution of the non-respondents (Models 4 and 5) where they show no significant difference. Down syndrome also shows statistically significantly low results until redistribution of the non-respondents (Model 5).

The key result from this analysis of both veteran's and children's data, is that the redistribution of non-respondents (irrespective of how this is done) is a critical factor in the estimation of validated responses. Across all conditions (in both veterans and children) approximately one-third of non-responses are allocated to a validated category using Models 4 and 5, although this varies from approximately 10% to 70%. If this one-third average is applied to all the conditions currently indicating significantly high results in Model 5, only NHL and leukaemia change from being significantly high to no significant difference. This is because these conditions rely heavily on the redistribution of non-respondents.

In summary, the results presented in this analysis would indicate that Models 1–3 should be those that are accepted for use in further modelling, the development of policy, or further investigation. The adoption of Model 3 seems to be the most appropriate. It recognises the contribution of validated responses in combination with those that seem likely to be validated. However, it removes the potential impact of non-respondents whose likelihood of having the conditions is unknown. Therefore, this model proposes that melanoma and prostate cancers in veterans and spina bifida and cleft lip/palate in veterans' children are the conditions which show significant and justifiable results that are elevated above the Morbidity Study derived community standard.

## 4.5 Conclusions

The Validation Study has been able to provide good evidence that indicates a high prevalence of several conditions in veterans and causes of death and conditions in their children. The outcomes of the Validation Study use the community standards derived in the Morbidity Study as a basis. The results depend on the quality of the Morbidity Study estimates and the redistribution of the not able to be validated conditions proportionally between the validated and not validated conditions (Model 3).

The results for the veterans are as follows:

- Melanoma of the skin and prostate cancer show significantly higher prevalence in veterans than in the Australian community standard.
- Breast and eye cancer, non-Hodgkin's lymphoma and leukaemia show no significant difference in prevalence between the veterans and the Australian community standard.
- Colorectal cancer, lung cancer, soft tissue sarcoma, and testis cancer show significantly lower prevalence in veterans than the Australian community standard.
- Cancer of the head and neck, other cancers and total cancers do not have a corresponding community standard, and one could not be derived in a way that was compatible with the prevalence data, so no assessment of their significance can be made.
- Motor neurone disease and multiple sclerosis were not addressed in this study. A separate study will be undertaken to validate these conditions.

The results for the veterans' children show:

- Spina bifida maxima and cleft lip/palate show significantly higher prevalence in veterans' children than in the Australian community standard.
- Deaths due to accidents and deaths due to illnesses show significantly higher prevalence in veterans' children than in the Australian community standard.
- Suicides are three times more prevalent in veteran's children than the Australian community standard.
- Wilm's tumour and anencephaly show no significant difference in prevalence between the veterans' children and the Australian community standard.
- Leukaemia, cancer of the nervous system, other cancers, Down syndrome, tracheo-eosophageal fistula and absent body parts all show significantly lower prevalence in veterans' children than the Australian community standard.
- Extra body parts does not have a corresponding community standard, nor could one be derived in a way that was compatible with the prevalence data, so no assessment of its significance can be made.

The results from this Validation Study show only a small part of the picture of the health of veterans and their children. The results from this study should be read in conjunction with other studies listed in the references of this document to gain an appreciation of the range of health issues confronting this group of people.

## 4.6 Recommendations

Statistical analysis of the Validation Study has prompted the following recommendations. It is recommended that:

- a validation study of motor neurone disease and multiple sclerosis in Vietnam veterans be undertaken as a matter of urgency in order to complete the validation process. This recommendation was made during the life of the Validation Study and is being planned by the AIHW, in conjunction with the Department of Veterans' Affairs, for completion in 2000;
- suicide in veterans' children be further investigated and the result drawn to the attention of the Vietnam Veterans' Counselling Service;
- cancer of the adrenal gland in veterans' children be further investigated and compared to a derived community standard; and
- Morbidity Study and Validation Study data be made accessible under appropriate conditions for use in further studies. Provision for this access is important to further work in this area. Approval for further work using these data would need to be gained from the ethics committees of the AIHW Ethics Committee, after liaison with the Commonwealth Department of Veterans' Affairs.



# Appendixes

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## **Appendix 1 Australian Institute of Health and Welfare Project team**

Project Director	Dr Paul Jelfs
Medical Adviser	Dr Paul Magnus
Project Managers	Ms Mieke van Doeland (July 1998–February 1999) Mr Phil Trickett (February 1999–October 1999)
Project Officers	Ms Michelle Maher (February 1999–November 1999) Ms Polly Wallace (July 1999–November 1999)
Support Staff	Ms Sally Martin (October 1998–March 1999) Mr Mark Alvey (October 1998–March 1999) Ms Sylvia Sheffield (October 1998–September 1999)
Other officers (Special tasks)	Ms Carolyn Dunn Mr Robert van der Hoek Ms Rebecca Bentley Ms Norma Briscoe Ms Janet Markey Ms Bonnie Abraham Mr Warwick Emanuel Mr Michael Paxton Ms Amanda Nobbs
Telephone staff	Ms Christine Treloar Ms Clara Jellie Dr Kathleen Strong Mr Malcolm Parkes Ms Bella Holmes
External referee	Dr Michael Adena

## **Appendix 2 Study Advisory Committee**

### **Chair**

Major General Paul Stevens AO  
Commissioner, Repatriation Commission

### **Members**

Dr Graeme Killer AO  
Principal Medical Adviser, Commonwealth Department of Veterans' Affairs

Mr Geoff Stonehouse OAM  
Division Head, Health Care & Services, Commonwealth Department of Veterans' Affairs

Dr Keith Horsley  
Senior Medical Adviser, Commonwealth Department of Veterans' Affairs

Mr Jim Dalton/Mrs Kay Grimsley  
Branch Head, Younger Veterans & Health Support, Commonwealth Department of Veterans' Affairs

Rear Admiral Guy Griffiths AO DSO DSC  
Representative, Australian Veterans and Defence Service Council

Mrs Colleen Thurgar AM  
Representative, Returned & Services League of Australia

Mr John Methven  
Representative, Vietnam Veterans' Association of Australia

Dr Paul Jelfs  
Head, Disease Registers Unit, Australian Institute of Health and Welfare

Dr Paul Magnus  
Medical Adviser, Australian Institute of Health and Welfare

Mr Phil Trickett  
Project Manager, Australian Institute of Health and Welfare

### **Observers**

Mr Gary Kent/Ms Victoria Lewis/Ms Danielle Moore  
Minister's Office

Ms Michelle Maher  
Australian Institute of Health and Welfare

Ms Polly Wallace  
Australian Institute of Health and Welfare

### **Secretariat**

Mr Dominic Melano  
Commonwealth Department of Veterans' Affairs

Ms Tania Salvestro  
Commonwealth Department of Veterans' Affairs

Ms Philippa Robinson/Mr Tim Sealey  
Commonwealth Department of Veterans' Affairs

## **Appendix 3 Medical Advisory Panel**

### **Chair**

Dr Paul Magnus

### **Members**

Dr Stephen Collins

Dr Simon Hammond

Dr Geoff Herkes

Dr Keith Horsley

Dr Paul Jelfs

Dr Allan Kermode

Dr Graeme Killer

Dr Paul Lancaster

Dr Jim McLeod

Dr Ted Stewart-Wynne

## **Appendix 4 Initial mail-out package to veterans**

- Survey cover letter
- Veterans' child survey form
- Veterans' survey form
- Letter from the Repatriation Commissioner
- Survey information sheet

Dear Veteran

Last year you took part in the initial stage of the 1997 Vietnam Veterans Health Study. As mentioned in the letter sent to you with that survey, all details have been transferred from the consultant group, AC Nielsen Research Pty Ltd, to the Australian Institute of Health and Welfare for confidential safekeeping and any follow-up. We are now writing to you about that follow-up.

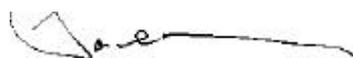
The initial results indicated that certain problems may occur more often among Vietnam veterans than in the general population. These problems include multiple sclerosis, motor neurone disease and cancers and, in veterans' children, birth defects, cancers and deaths from a range of causes.

It is necessary to look at these problems in more detail. According to records of the survey, you were among those affected by one or more of these problems. We hope you will now provide us with more details and allow us to follow up your response through medical sources, as explained in the enclosed package.

Would you please read the information sheet on the front of the enclosed package, complete the relevant form(s) and return by **December 11** or earlier. **Please be assured that at no time will the Institute pass to the Department of Veterans' Affairs any details that could identify you in any way.** You can see from the Commissioner's letter that this follow-up study has the endorsement of representatives of the ex-service community. However, you personally have not been identified to the Commissioner or to them in this process.

We urge you to continue in this study. This will help to build further policy for the benefit of all Vietnam veterans.

Yours sincerely,



Dr Paul Magnus  
Medical Director  
14 October, 1998

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>





**VIETNAM VETERANS VALIDATION STUDY**  
**IMPORTANT: PLEASE READ THE INFORMATION SHEET FIRST**

1. Our records show that in the initial study you indicated that you have been diagnosed with the following medical condition:

Please indicate the year and place this condition was first diagnosed 19..... in (State/Territory) .....

If unsure of the exact year, please indicate an approximate period .....

2a. To enable us to confirm this condition through medical records, will you give us permission to obtain medical information (relating to this condition only) from a medical practitioner or hospital or consult disease registers?: **(Please tick)** YES  **If Yes, go to 3** NO  **If No, go to 2b**

2b. If **No**, would you prefer to contact the doctor yourself? In this case we will send you the medical from which you will need to either send or take to an appropriate doctor as soon as possible. **(Please tick)** YES  **If Yes, go to 4** NO  **If No, go to 4**

3. Please indicate an appropriate medical practitioner/practice/hospital with information about your condition.

*(Note: if you cannot give us these details, please give any information that may help our follow-up)*

**PLEASE PRINT CLEARLY**

Doctor's name/practice/hospital .....

Doctor's phone number ( ).....

Doctor's address Street .....  
 Suburb..... State ..... Postcode.....

If you have any documentation which may assist us in this study, it would be helpful if you enclose a copy with your reply.

**DO NOT SEND ORIGINALS**

4. Your date of birth ...../...../19.....  
 Day Month Year

5. Can we contact you again if we need more details from you for this study **(please tick)** YES  NO  **If No, go to 6**  
 If Yes, what is your phone number ( ) .....Home / Work  
 Other contact details (e.g. fax, E-mail) .....

6. Your name and address:

Please correct the above details where necessary. If any information is missing, please write this in the space above including given names and any other names by which you are known. This will allow us to identify your relevant medical records more easily. **PLEASE PRINT CLEARLY**

7. **Signed** .....

Date ...../...../1998  
 Day Month Year

**HELPLINE 1800 236 166**

**PLEASE SEND THIS FORM IN THE REPLY PAID ENVELOPE BY MARCH 26 TO:**

REPLY PAID 1297  
 VIETNAM VETERAN VALIDATION STUDY  
 AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
 LOCKED BAG 8550  
 CANBERRA ACT 2601  
 The Institute will treat your answers with strict confidentiality

**THANK YOU FOR YOUR PARTICIPATION.**



The letter from the Services Member, Repatriation Commission, is not included.

## INFORMATION SHEET – VIETNAM VETERANS VALIDATION STUDY

**PLEASE READ THIS SHEET CAREFULLY BEFORE YOU COMPLETE THE FORM(S)**

In the enclosed package you will have received survey form(s) that relate to yourself (green) or your children (blue). This means that you indicated in the 1997 Vietnam Veterans Health Survey that you or your children have had one of the health problems now being studied.

Participation in this validation stage of the study is voluntary, but it is **vital** to get an accurate picture, and this needs your participation. If you decide to participate, it would help us most if you give your full consent by ticking **Yes** where relevant and completing all details on each form. However, other options are provided.

We are aware that we are asking you about issues that can be deeply personal and bring up painful memories. Your participation is much appreciated. We have done all we can to ensure that the details on your form(s) are correct. If you find any incorrect or missing information would you please accept our apologies and let us know the correct details.

### Completing the survey forms

The survey forms request information about you or your child's health conditions. They also seek your consent to confirm these conditions with a doctor, hospital or disease register. If you have any documentation which might prove helpful in confirming these conditions it would be helpful if you enclose a copy with your reply. There are two types of survey forms:

1. *Veteran's form (Green)* - You should complete **one form for each of your conditions**. Each condition is printed at the top of the form.
2. *Veteran's Child form (Blue)* - It is important that you provide details relating to each child's condition or death on the blue form(s) - **one form per child**.

### Confidentiality

All survey details will be held at the Australian Institute of Health and Welfare (AIHW) and treated with the strictest confidentiality. The AIHW is bound by strict confidentiality provisions in its Act (1987) and the privacy principles in the Privacy Act. The study is monitored by the AIHW's Ethics Committee. You can be assured that only de-identified information will be disclosed as a result of this study.

### Need more help?

If you would like more information about the study or assistance completing the form, you are welcome to call the **FREECALL HELPLINE - 1800 236 166**.

We will be very happy to answer your questions **Monday to Friday 9 a.m.-7 p.m. (EST)**.

For calls outside these hours, leave your name and phone number and we will return your call.

Please return your consent form in the enclosed reply paid envelope by **NOVEMBER 6** to:

**REPLY PAID 1297**

**Vietnam Veterans Validation Study  
Australian Institute of Health and Welfare  
LOCKED BAG 8550  
CANBERRA ACT 2601**

**THANKYOU FOR YOUR PARTICIPATION**



## **Appendix 5 First reminder mail-out package to veterans**

- Letter from the Minister
- Survey reminder letter

The letter from the Minister for Veterans' Affairs is not included.

The letter from the Minister for Veterans' Affairs is not included.

Dear Veteran

I am writing about the **Vietnam Veterans Validation Survey** that we are currently conducting.

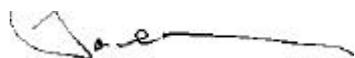
According to our records you, along with approximately 7,000 other Vietnam veterans, were sent a survey package in October. At the time of writing we have received a significant number of responses, however we have not yet received your reply. **If you have recently returned your form(s), thank you for your reply. If not, we would appreciate your response and ask that you return your form as soon as possible to the address below. We have extended our survey follow up time until Friday the 4<sup>th</sup> of December 1998.**

If you did **not** receive the survey package, have misplaced the form(s), or need assistance in completing the form(s) please contact us for assistance on the freecall help line **1800 236 166**.

We would like to again assure you that your information will not be provided to the Department of Veterans' Affairs and will not threaten any claims pending or payments you may have through the Department. Your information will be held in strict confidence at the AIHW.

I urge you to participate in this Validation Study. The information you contribute is important in confirming matters of concern in the health of Vietnam Veterans.

Yours sincerely,



Dr Paul Magnus  
23 November, 1998

**Reply Paid 1297  
Vietnam Veterans Validation Study  
Australian Institute of Health and Welfare  
Locked Bag 8550  
Canberra ACT 2601**

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

## **Appendix 6 Second reminder mail-out package to veterans**

- Survey reminder letter
- Veteran survey form
- Veterans' child survey form
- Letter from the Minister
- Survey information sheet

Dear Veteran,

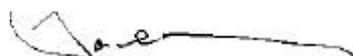
In 1997 you took part in the Vietnam Veterans Health Study which showed that certain health problems may occur more often among Vietnam veterans and their children than in the general population.

It is vitally important for the long term benefit of veterans' children that further documentation of their health problems occurs now. The AIHW has been given the task of undertaking this study. By completing a very short survey about your children's health you can assist in the development of policy regarding the children of all veterans.

Please read the attached information sheet, complete the blue form(s) and return them by **February 24** or earlier. You should note that your response is **confidential and will not be passed to the Department of Veterans' Affairs**.

This is the **last chance** to participate in this study and in combination with the veterans ex-service organisations we urge you to participate.

Yours sincerely,



Dr Paul Magnus  
Medical Adviser  
9 February, 1999

For health and welfare  
statistics and information

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

**VIETNAM VETERANS VALIDATION STUDY**  
**IMPORTANT: PLEASE READ THE INFORMATION SHEET FIRST**

1. Our records show that in the initial study you indicated that you have been diagnosed with the following medical condition:

Please indicate the year and place this condition was first diagnosed 19..... in (State/Territory) .....  
 If unsure of the exact year, please indicate an approximate period .....

2a. To enable us to confirm this condition through medical records, will you give us permission to obtain medical information (relating to this condition only) from a medical practitioner or hospital or consult disease registers?: **(Please tick)** YES  NO   
If Yes, go to 3 If No, go to 2b

2b. If **No**, would you prefer to contact the doctor yourself? YES  NO   
 In this case we will send you the medical from which you will need to either send or take to an appropriate doctor as soon as possible. **(Please tick)** If Yes, go to 4 If No, go to 4

3. Please indicate an appropriate medical practitioner/practice/hospital with information about your condition.

*(Note: if you cannot give us these details, please give any information that may help our follow-up)*

**PLEASE PRINT CLEARLY**

Doctor's name/practice/hospital .....

Doctor's phone number ( ).....

Doctor's address Street .....  
 Suburb..... State ..... Postcode.....

If you have any documentation which may assist us in this study, it would be helpful if you enclose a copy with your reply.

**DO NOT SEND ORIGINALS**

4. Your date of birth ...../...../19.....  
 Day Month Year

5. Can we contact you again if we need more details from you for this study **(please tick)** YES  NO   
 If Yes, what is your phone number ( ) .....Home / Work If No, go to 6  
 Other contact details (e.g. fax, E-mail) .....

6. Your name and address:

Please correct the above details where necessary. If any information is missing, please write this in the space above including given names and any other names by which you are known. This will allow us to identify your relevant medical records more easily. **PLEASE PRINT CLEARLY**

7. **Signed** .....

Date ...../...../1998  
 Day Month Year

**HELPLINE 1800 236 166**

**PLEASE SEND THIS FORM IN THE REPLY PAID ENVELOPE BY MARCH 26 TO:**

REPLY PAID 1297  
 VIETNAM VETERAN VALIDATION STUDY  
 AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
 LOCKED BAG 8550  
 CANBERRA ACT 2601  
 The Institute will treat your answers with strict confidentiality

**THANK YOU FOR YOUR PARTICIPATION.**







The letter from the Minister for Veterans' Affairs is not included.

The letter from the Minister for Veterans' Affairs is not included.

## INFORMATION SHEET – VIETNAM VETERANS VALIDATION STUDY

**PLEASE READ THIS SHEET CAREFULLY BEFORE YOU COMPLETE THE FORM(S)**

In the enclosed package you will have received survey form(s) that relate to yourself (green) or your children (blue). This means that you indicated in the 1997 Vietnam Veterans Health Survey that you or your children have had one of the health problems now being studied.

Participation in this validation stage of the study is voluntary, but it is **vital** to get an accurate picture, and this needs your participation. If you decide to participate, it would help us most if you give your full consent by ticking **Yes** where relevant and completing all details on each form. However, other options are provided.

We are aware that we are asking you about issues that can be deeply personal and bring up painful memories. Your participation is much appreciated. We have done all we can to ensure that the details on your form(s) are correct. If you find any incorrect or missing information would you please accept our apologies and let us know the correct details.

### Completing the survey forms

The survey forms request information about you or your child's health conditions. They also seek your consent to confirm these conditions with a doctor, hospital or disease register. If you have any documentation which might prove helpful in confirming these conditions it would be helpful if you enclose a copy with your reply. There are two types of survey forms:

3. *Veteran's form (Green)* - You should complete **one form for each of your conditions**. Each condition is printed at the top of the form.
4. *Veteran's Child form (Blue)* - It is important that you provide details relating to each child's condition or death on the blue form(s) - **one form per child**.

### Confidentiality

All survey details will be held at the Australian Institute of Health and Welfare (AIHW) and treated with the strictest confidentiality. The AIHW is bound by strict confidentiality provisions in its Act (1987) and the privacy principles in the Privacy Act (1988). The study is monitored by the AIHW's Ethics Committee. You can be assured that only de-identified information will be disclosed as a result of this study.

### Need more help?

If you would like more information about the study or assistance completing the form, you are welcome to call the **FREECALL HELPLINE - 1800 236 166**.

We will be very happy to answer your questions **Monday to Friday 9am-7pm (EST)**.

For calls outside these hours, leave your name and phone number and we will return your call.

Please return your consent form in the enclosed reply paid envelope by **NOVEMBER 6** to:

**REPLY PAID 1297**

**Vietnam Veterans Validation Study  
Australian Institute of Health and Welfare  
LOCKED BAG 8550**

**CANBERRA ACT 2601**

**THANKYOU FOR YOUR PARTICIPATION**



## **Appendix 7 Apology letter to veterans**

- Apology letter to veterans

Dear Veteran

I am writing about the **Vietnam Veterans Validation Survey** that we are currently conducting.

According to our records you were sent a survey package in October and we received your return. We thank you for your response. Unfortunately you were among a small number of veterans that received an incomplete package due to a data processing error. To correct this we have enclosed one or more blue forms which relate to any children who have been affected by the problems currently under study. This may be one of the medical conditions which we have listed on the form or it may be a death.

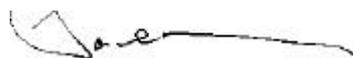
Please accept our sincere apologies and be assured that we have taken corrective action for all veterans affected by the error. We would appreciate it if you would complete and return the form(s) as soon as possible. If you find you now have more forms than you need, you can return any extra forms empty. On the other hand, if you believe that you need more forms or if you need assistance in completing the form(s), please contact us on the freecall helpline **1800 236 166**.

The follow up date for this very important health survey has been extended to **Wednesday the 24<sup>th</sup> of February 1999**.

We would like to assure you again that your information will not be provided to the Department of Veterans' Affairs and will not threaten any claims pending. Your information will be held in strict confidence at the AIHW.

The information you contribute is important in confirming matters of concern in the health of Vietnam Veterans and their children. I thank you for your help in this study.

Yours sincerely,



Dr Paul Magnus  
3 February, 1999

For health and welfare  
statistics and information

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

## **Appendix 8 Initial mail-out package to veterans' children**

- Survey cover letter
- Child survey form
- Survey information sheet

Dear Veterans' Child,

In 1997 and 1998 your father took part in the Vietnam Veterans Health Study. All details from that study are held by the Australian Institute of Health and Welfare for confidential safekeeping and for follow-up. We are now conducting that follow-up.

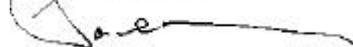
The initial results of the study indicated that certain problems may occur more often among Vietnam veterans and their families than in the general population. These problems include multiple sclerosis, motor neurone disease and cancers in veterans themselves and, in veterans' children, birth defects, cancers and deaths from a range of causes.

It is necessary to look at these problems in more detail and to validate a number of the reported conditions by obtaining medical confirmation or by consulting health registers. According to records of the survey, you were among those affected by one or more of these conditions. One of your parents has provided us with some details and we now hope you will provide us with further details and allow us to follow up your response through medical sources, as explained in the enclosed package.

Would you please read the information sheet on the front of the enclosed package, complete the relevant form(s) and return by **February 12** or earlier. **Please be assured that your answers will be completely confidential and that at no time will the AIHW pass to the Department of Veterans' Affairs any details that could identify you or your father in any way.**

We urge you to take part in this study. This will help to build further policy for the benefit of all Vietnam veterans and their children.

Yours sincerely,



Dr Paul Magnus  
Medical Adviser  
22 January 1999

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

**VIETNAM VETERANS VALIDATION STUDY – FOLLOW UP OF VETERAN’S CHILDREN  
IMPORTANT: PLEASE READ THE INFORMATION SHEET FIRST**

1. Our records show that in the initial study your father indicated that you have been diagnosed with the following medical condition:

Please indicate the year and place this condition was first diagnosed 19..... in (State/Territory) .....

If unsure of the exact year, please indicate an approximate period .....

2a. To enable us to confirm this condition through medical records, will you give us permission to obtain medical information (relating to this condition only) from a medical practitioner or hospital or consult disease registers?: **(Please tick)** YES  NO   
If Yes, go to 3 If No, go to 2b

2b. If no, would you prefer to contact the doctor yourself? YES  NO   
 In this case we will send you the medical from which you will need to either send or take to an appropriate doctor as soon as possible. **(Please tick)** If Yes, go to 4 If No, go to 4

3. Please indicate an appropriate medical practitioner/practice/hospital with information about your condition.

(Note: if you cannot give us these details, please give any information that may help our follow-up)

**PLEASE PRINT CLEARLY**

Doctor's name/practice/hospital .....

Doctor's phone number ( ) .....

Doctor's address Street .....

Suburb..... State .....Postcode.....

If you have any documentation which may assist us in this study, it would be helpful if you enclose a copy with your reply.

**DO NOT SEND ORIGINALS**

4. Your date of birth ...../...../19.....  
 Day Month Year

5. Can we contact you again if we need more details from you for this study **(please tick)** YES  NO   
 If Yes, what is your phone number ( ) .....Home / Work If No, go to 6  
 Other contact details (e.g. fax, E-mail) .....

6. Your name and address:

Please correct the above details where necessary. If any information is missing, please write this in the space above including given names and any other names by which you are known. This will allow us to identify your relevant medical records more easily. **PLEASE PRINT CLEARLY**

7. **Signed** .....

Date ...../...../19....

Day Month Year

**HELPLINE 1800 236 166**

**PLEASE SEND THIS FORM IN THE REPLY PAID ENVELOPE  
BY MARCH 26 TO:**

**REPLY PAID 1297  
VIETNAM VETERAN VALIDATION STUDY  
AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
LOCKED BAG 8550  
CANBERRA ACT 2601**

The Institute will treat your answers with strict confidentiality.

**THANK YOU FOR YOUR PARTICIPATION**



## INFORMATION SHEET - VIETNAM VETERANS VALIDATION STUDY

**PLEASE READ THIS SHEET CAREFULLY BEFORE YOU COMPLETE THE FORM(S)**

Enclosed with this letter you will have received a yellow survey form(s). This means that your father indicated in the Vietnam Veterans Health Survey that you have had one of the health problems now being studied.

Participation in this validation stage of the study is voluntary, but it is **vital** to get an accurate picture, and this needs your participation. If you decide to participate, it would help us most if you give your full consent by ticking **Yes** where relevant and completing all details on each form. However, other options are provided.

We are aware that we are asking you about issues that can be deeply personal and bring up painful memories. Your participation is much appreciated. We have done all we can to ensure that the details on your form(s) are correct. If you find any incorrect or missing information would you please accept our apologies and let us know the correct details.

### **Completing the survey forms**

The survey forms request information about your health conditions. They also seek your consent to confirm these conditions with a doctor, hospital or disease register. If you have any documentation which might prove helpful in confirming these conditions it would be helpful if you enclose a copy with your reply.

### **Confidentiality**

All survey details will be held at the Australian Institute of Health and Welfare (AIHW) and treated with the strictest confidentiality. The AIHW is bound by strict confidentiality provisions in its Act (1987) and the privacy principles in the Privacy Act (1988). The study is monitored by the AIHW's Ethics Committee. You can be assured that only de-identified information will be disclosed as a result of this study.

### **Need more help?**

If you would like more information about the study or assistance completing the form, you are welcome to call the **FREECALL HELPLINE - 1800 236 166**.

We will be very happy to answer your questions **Monday to Friday 9am-7pm (EST)**.

For calls outside these hours, leave your name and phone number and we will return your call.

Please return your consent form in the enclosed reply paid envelope by **February 12** to:

**REPLY PAID 1297**  
**Vietnam Veterans Validation Study**  
**Australian Institute of Health and Welfare**  
**LOCKED BAG 8550**  
**CANBERRA ACT 2601**

**THANK YOU FOR YOUR PARTICIPATION**



## **Appendix 9 Reminder mail out package to veterans' children**

- Survey reminder letter
- Child survey form
- Survey information sheet

Dear Veterans' Child,

Recently we sent a package to you, asking for your support so we can medically confirm a number of medical conditions reported among the children of Vietnam veterans.

This was as a result of your father taking part in the Vietnam Veterans Health Study in 1997/98 where he reported that you were among those affected by one or more of the conditions specified on the attached form(s). One of your parents has provided us with your contact details and we now ask you to give permission for us to contact a medical source to confirm these conditions.

**Your response is important. The government has given a commitment to respond to the findings if we can medically confirm that the children of Vietnam Veterans are more likely to suffer certain health problems than the general population.**

**We cannot go any further with this study unless we receive your permission to confirm these reported conditions.**

Please read the information sheet on the front of the enclosed package, complete the relevant form(s) and return by **June 11** or earlier.

Your answers will be completely confidential and at no time will the AIHW give any details to the Department of Veterans' Affairs that could identify you or your father in any way.

**Please help us by returning your forms. Your response may benefit Vietnam veterans and their children.**

Yours sincerely



Dr Paul Magnus  
Medical Adviser  
24 May 1999

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

**VIETNAM VETERANS VALIDATION STUDY – FOLLOW UP OF VETERAN’S CHILDREN  
IMPORTANT: PLEASE READ THE INFORMATION SHEET FIRST**

1. Our records show that in the initial study your father indicated that you have been diagnosed with the following medical condition:

Please indicate the year and place this condition was first diagnosed 19..... in (State/Territory) .....

If unsure of the exact year, please indicate an approximate period .....

2a. To enable us to confirm this condition through medical records, will you give us permission to obtain medical information (relating to this condition only) from a medical practitioner or hospital or consult disease registers?: **(Please tick)** YES  If Yes, go to 3 NO  If No, go to 2b

2b. If no, would you prefer to contact the doctor yourself? In this case we will send you the medical from which you will need to either send or take to an appropriate doctor as soon as possible. **(Please tick)** YES  If Yes, go to 4 NO  If No, go to 4

3. Please indicate an appropriate medical practitioner/practice/hospital with information about your condition.

(Note: if you cannot give us these details, please give any information that may help our follow-up)

**PLEASE PRINT CLEARLY**

Doctor's name/practice/hospital .....

Doctor's phone number ( ).....

Doctor's address Street .....  
Suburb..... State .....Postcode.....

If you have any documentation which may assist us in this study, it would be helpful if you enclose a copy with your reply.

**DO NOT SEND ORIGINALS**

4. Your date of birth ...../...../19.....  
Day Month Year

5. Can we contact you again if we need more details from you for this study **(please tick)** YES  NO   
If Yes, what is your phone number ( ) .....Home / Work If No, go to 6  
Other contact details (e.g. fax, E-mail) .....

6. Your name and address:

Please correct the above details where necessary. If any information is missing, please write this in the space above including given names and any other names by which you are known. This will allow us to identify your relevant medical records more easily. **PLEASE PRINT CLEARLY**

7. **Signed** .....

Date ...../...../19....  
Day Month Year

**HELPLINE 1800 236 166**

**PLEASE SEND THIS FORM IN THE REPLY PAID ENVELOPE  
BY MARCH 26 TO:**

**REPLY PAID 1297  
VIETNAM VETERAN VALIDATION STUDY  
AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
LOCKED BAG 8550  
CANBERRA ACT 2601**

The Institute will treat your answers with strict confidentiality.

**THANK YOU FOR YOUR PARTICIPATION**



## INFORMATION SHEET - VIETNAM VETERANS VALIDATION STUDY

**PLEASE READ THIS SHEET CAREFULLY BEFORE YOU COMPLETE THE FORM(S)**

Enclosed with this letter you will have received a yellow survey form(s). This means that your father indicated in the Vietnam Veterans Health Survey that you have had one of the health problems now being studied.

Participation in this validation stage of the study is voluntary, but it is **vital** to get an accurate picture, and this needs your participation. If you decide to participate, it would help us most if you give your full consent by ticking **Yes** where relevant and completing all details on each form. However, other options are provided.

We are aware that we are asking you about issues that can be deeply personal and bring up painful memories. Your participation is much appreciated. We have done all we can to ensure that the details on your form(s) are correct. If you find any incorrect or missing information would you please accept our apologies and let us know the correct details.

### **Completing the survey forms**

The survey forms request information about your health conditions. They also seek your consent to confirm these conditions with a doctor, hospital or disease register. If you have any documentation which might prove helpful in confirming these conditions it would be helpful if you enclose a copy with your reply.

### **Confidentiality**

All survey details will be held at the Australian Institute of Health and Welfare (AIHW) and treated with the strictest confidentiality. The AIHW is bound by strict confidentiality provisions in its Act (1987) and the privacy principles in the Privacy Act (1988). The study is monitored by the AIHW's Ethics Committee. You can be assured that only de-identified information will be disclosed as a result of this study.

### **Need more help?**

If you would like more information about the study or assistance completing the form, you are welcome to call the **FREECALL HELPLINE - 1800 236 166**.

We will be very happy to answer your questions **Monday to Friday 9am-7pm (EST)**.

For calls outside these hours, leave your name and phone number and we will return your call.

Please return your consent form in the enclosed reply paid envelope by **February 12** to:

**REPLY PAID 1297**

**Vietnam Veterans Validation Study**

**Australian Institute of Health and Welfare**

**LOCKED BAG 8550**

**CANBERRA ACT 2601**

**THANK YOU FOR YOUR PARTICIPATION**



# Appendix 10 Telephone prompting protocol for veterans and children

## Telephone prompting protocol

*[Use the list generated for each telephonist, phone between 5.30 p.m. and 9 p.m. only.*

*Extract the veteran's or child's record from the database prior to calling.*

*Ask for the veteran/child by name and arrange to call back if they are unavailable.]*

Hello, I'm *[Interviewer's full name]* from the Australian Institute of Health and Welfare. I am ringing in regards to the **Vietnam Veterans Validation Study**. You may have seen this survey discussed in the newspapers and on the radio lately.

I hope that you have received a survey package from us in the mail in the last day or so.

*[Did they? If so continue; if not check details in database and arrange for new survey package to be distributed immediately.]*

I would like to check that there is no problem completing the form/s (green, blue, yellow). You can return it/them to the AIHW in the free reply paid envelope – the closing date is *[Insert agreed date]*.

I can help you complete the form over the phone if you like *[Help the veteran or his child to complete the form where possible. Explain the use of the data, if needed. Encourage respondent to return the form, discussing issues such as the following]*

- This is a very important study into the health of Vietnam veterans.
- The results of this study will help to influence government policy for Vietnam veterans and their children. This might mean extending the range of illnesses covered.
- It is important that we get your signature to help access your medical records from the doctor you nominate.

We appreciate your help with this survey.

Thank you.

*[If the veteran or his child states that they do not wish to continue with the survey, then indicate this in the data form and assure the veteran or child that they will not be contacted again.*

*If the veteran indicates that he does have the condition (or his child) record this as a 'not validated' condition in the dat base and indicate the validation source as the veteran.]*

## **Appendix 11 Doctor mail-out package**

- Survey cover letter
- Doctor survey form

Dear Validation Source,  
**Vietnam Veterans Validation Study**  
**Patient**

**Veteran/Veterans' Child**

**Self- reported condition(s)**

**Diagnosed Condition**

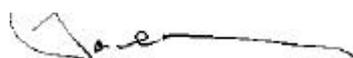
I am writing to you as part of an important study into the health of Australian Vietnam Veterans. Self-reporting by veterans in the Vietnam Veterans' Health Study (1997) suggests excess rates of certain serious conditions. The Department of Veterans' Affairs has commissioned the Australian Institute of Health and Welfare to undertake a validation study of selected conditions in approximately 7,000 veterans and their children.

The veteran/patient mentioned above has provided your name and their permission to approach you to validate their condition or that of their child. A signed patient consent form is attached. Reimbursement of costs you incur in completing this survey can be made, including the cost of any consultation with the patient in relation to this study. To this end could you please complete the enclosed form and return it by fax or mail by **18<sup>th</sup> June**. I may contact you in the next few days to follow up this request. For information please contact the Help line **1800 236 166**.

We should stress that any information you or your patients provide is collected under the strict confidentiality provisions of the Australian Institute of Health and Welfare Act (1987) and **will not be used in a way that could identify individual patients, doctors or hospitals**. It is important to note that this personalised information will not be released to the Department of Veterans' Affairs or any claims authority.

Your input into this landmark Australian study is vital in shaping policies for the best health care of veterans and their children. Thank you for your co-operation.

Yours sincerely



Dr Paul Magnus  
Medical Adviser  
26 May, 1999

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

**VIETNAM VETERANS VALIDATION STUDY  
MEDICAL VALIDATION FORM – CONFIDENTIAL**

To:

*Please correct any of these*



**1. DETAILS OF THE PATIENT OR FORMER PATIENT**

Patient's name:  
Date of birth:  
Study ID number:

Address:

**2. VALIDATION**

**Diagnosis**

According to our records this patient has reportedly been diagnosed with the following condition

«Diagnosed\_Condition»

Year of diagnosis (approx): «Diagnosis\_Year»  
Place of diagnosis: «Diagnosis\_State»

**Death**

According to our records this patient has reportedly died due to the following cause

Date of death:  
Place of death:

**From your own knowledge or medical records please complete (tick) the statements below.**

- This person has had «Diagnosed\_Condition» Yes  No  Not able to say   
If the person has not had «Diagnosed\_Condition» but has had a similar condition or one that may be confused with it, please specify the condition:.....
- This person has died Yes  No  Not able to say   
If possible please specify the cause of death .....

**3. LEUKAEMIA AND SPINA BIFIDA**

**If you are confirming leukaemia or spina bifida in a veteran or their child, please indicate the type below.**

Acute lymphatic leukaemia  Acute myeloid leukaemia  Type unknown   
Chronic lymphatic leukaemia  Chronic myeloid leukaemia

Spina bifida

- present in clinically significant form
- present but not in a clinically significant form (e.g. occulta type, incidental finding)

**4. COMPLETING DOCTOR'S SIGNATURE AND OTHER INFORMATION**

Signature .....  
Date ...../...../.....



Name .....  
(if not the same as above)

Address.....

State ..... Post code .....  
Ph. (.....) .....

**FREECALL HELPLINE 1800 236 166**  
Dr Paul Magnus, Mr Phil Trickett

**PLEASE RETURN BY 27<sup>th</sup> August  
TO THE REPLY PAID ADDRESS  
OR VIA FAX (02) 62441191**

**REPLY PAID 1297  
LOCKED BAG 8550  
AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
CANBERRA ACT 2601**

## **Appendix 12 Reminder mail-out package to doctors**

- Survey cover letter
- Doctor survey form

Dear Validation Source,

**Vietnam Veterans Validation Study**

Patient

**Veteran/Veterans' Child**

**Self- reported condition(s)**

**Diagnosed Condition**

Recently we sent you a Vietnam Veterans Validation Study package asking you to assist in validating the above condition reported by one of your patients. To date we have not received your reply. The contribution of doctors to this validation process is critical to the success of this important study and directly relevant to government policies supporting Veterans and their children.

The person mentioned above has provided your name and their permission (see consent form) to approach you to validate their condition. This person is one of the few outstanding for follow-up among the approximately 7,000 Vietnam Veterans and their children.

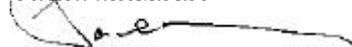
We would appreciate it if you could complete the enclosed form and return it by the **16<sup>th</sup> July**. We may contact you by telephone in the next few days in case you have any queries, or you may contact me through the freecall Help line **1800 236 166**.

**Reimbursement of costs you incur in completing this survey can be made, including the cost of any consultation with the patient in relation to this study.**

We should stress that any information you or your patients provide is collected under the strict confidentiality provisions of the Australian Institute of Health and Welfare Act (1987) and **will not be used in a way that could identify individual patients, doctors or hospitals**. It is important to note that this personalised information will not be released to the Department of Veterans' Affairs or any claims authority.

Your input into this landmark Australian study is vital in shaping policies for the best health care of veterans and their children. Thank you for your co-operation.

Yours sincerely



Dr Paul Magnus  
Medical Adviser  
28 June, 1999

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

**VIETNAM VETERANS VALIDATION STUDY  
MEDICAL VALIDATION FORM – CONFIDENTIAL**

To:

*Please correct any of these*



**1. DETAILS OF THE PATIENT OR FORMER PATIENT**

Patient's name:  
Date of birth:  
Study ID number:

Address:

**2. VALIDATION**

**Diagnosis**

According to our records this patient has reportedly been diagnosed with the following condition

«Diagnosed\_Condition»

Year of diagnosis (approx): «Diagnosis\_Year»  
Place of diagnosis: «Diagnosis\_State»

**Death**

According to our records this patient has reportedly died due to the following cause

Date of death:  
Place of death:

**From your own knowledge or medical records please complete (tick) the statements below.**

1. This person has had «Diagnosed\_Condition» Yes  No  Not able to say   
If the person has not had «Diagnosed\_Condition» but has had a similar condition or one that may be confused with it, please specify the condition:.....
2. This person has died Yes  No  Not able to say   
If possible please specify the cause of death .....

**3. LEUKAEMIA AND SPINA BIFIDA**

**If you are confirming leukaemia or spina bifida in a veteran or their child, please indicate the type below.**

Acute lymphatic leukaemia  Acute myeloid leukaemia  Type unknown   
Chronic lymphatic leukaemia  Chronic myeloid leukaemia

Spina bifida

- present in clinically significant form
- present but not in a clinically significant form (e.g. occulta type, incidental finding)

**4. COMPLETING DOCTOR'S SIGNATURE AND OTHER INFORMATION**

Signature .....  
Date ..../..../.....



Name .....  
(if not the same as above)

Address.....

State ..... Post code .....  
Ph. (.....) .....

**FRECALL HELPLINE 1800 236 166**  
Dr Paul Magnus, Mr Phil Trickett

**PLEASE RETURN BY 27<sup>th</sup> August  
TO THE REPLY PAID ADDRESS  
OR VIA FAX (02) 62441191**

**REPLY PAID 1297  
LOCKED BAG 8550  
AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
CANBERRA ACT 2601**

# Appendix 13 Telephone prompting protocol for medical practitioners

## Telephone prompting protocol

*[Use the list generated for each telephonist, phone between 9 a.m. and 5 p.m. only.*

*Extract the veteran or child's record from the database prior to calling.]*

Hello, I'm *[Interviewer's full name]* from the Australian Institute of Health and Welfare. I am ringing in regards to the **Vietnam Veterans Validation Study**.

A couple of weeks ago we sent a survey package to *[Insert medical practitioner's name]* and I am calling to confirm that it was received.

*[Was it? If so, continue; if not, check details in database and arrange for new survey package to be distributed immediately.]*

Do you know if *[Insert medical practitioner's name]* has looked at the survey and if it will be returned?

*[If yes, thank the receptionist and hang up. If no, continue.]*

Would you be able to let *[Insert medical practitioner's name]* know that I called and encourage him to return the survey at his/her earliest convenience.

We appreciate your help with this survey.

Thank you

## **Appendix 14 Mail-out packages for self-validation by veterans and veterans' children with help from their doctors**

- Survey cover letter for the veteran/veteran's child
- Survey cover letter for the doctor
- Doctor survey form
- Survey information sheet

Dear Veteran/Veterans' Child,

**Re: Vietnam Veterans Validation Survey**

Thank you for your response to the survey. You indicated that you would prefer to contact your doctor yourself to assist in the validation of your health conditions, or those of your children. I enclose the Medical Validation form(s) and a letter to your doctor for this purpose.

Could you please contact your doctor and arrange for him/her to complete the enclosed validation form(s). We ask that you or your doctor return the form(s) by the **30th April** to the address or fax number on the form.

We should stress that any information your doctor provides is collected under the strict confidentiality provisions of the Australian Institute of Health and Welfare Act (1987). It is important to note that this personalised information will not be released to the Department of Veterans' Affairs or any claims authority.

Reimbursement of costs you or your doctor incur in completing this survey can be made, including the cost of a consultation in relation to this study. Such claims should be sent directly to the address or fax number on the form. Claims should **not** be made directly to the Department of Veterans' Affairs.

For more information please contact the freecall Help line 1800 236 166. Thank you for your co-operation.

Yours sincerely,



Dr Paul Magnus  
Medical Adviser  
9 April, 1999

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

Dear Validation Source,  
**Vietnam Veterans Validation Study**  
**Patient**

Mr «First\_Name» «Second\_Name» «Surname»

**Self- reported condition(s)**

«Diagnosed\_Condition»

I am writing to you as part of an important study into the health of Australian Vietnam Veterans. Self-reporting by veterans in the Vietnam Veterans' Health Study (1997) suggests excess rates of certain serious conditions. The Department of Veterans' Affairs has commissioned the Australian Institute of Health and Welfare to undertake a validation study of selected conditions in approximately 7,000 veterans and their children.

The veteran/patient mentioned above has provided your name and their permission to approach you to validate their condition or that of their child. A signed patient consent form is attached. Reimbursement of costs you incur in completing this survey can be made, including the cost of any consultation with the patient in relation to this study. To this end could you please complete the enclosed form and return it by fax or mail by **30<sup>th</sup> April**. I may contact you in the next few days to follow up this request. For information please contact the Help line **1800 236 166**.

We should stress that any information you or your patients provide is collected under the strict confidentiality provisions of the Australian Institute of Health and Welfare Act (1987) and **will not be used in a way that could identify individual patients, doctors or hospitals**. It is important to note that this personalised information will not be released to the Department of Veterans' Affairs or any claims authority.

Your input into this landmark Australian study is vital in shaping policies for the best health care of veterans and their children. Thank you for your co-operation.

Yours sincerely,



Dr Paul Magnus  
Medical Adviser  
9 April 1999

For health and welfare  
statistics and information

6A Traeger Court  
Fern Hill Park  
Bruce ACT

GPO Box 570  
Canberra ACT 2601

Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

**VIETNAM VETERANS VALIDATION STUDY  
MEDICAL VALIDATION FORM – CONFIDENTIAL**

To:

*Please correct any of these*



**1. DETAILS OF THE PATIENT OR FORMER PATIENT**

Patient's name:  
Date of birth:  
Study ID number:

Address:

**2. VALIDATION**

**Diagnosis**

According to our records this patient has reportedly been diagnosed with the following condition

«Diagnosed\_Condition»

Year of diagnosis (approx): «Diagnosis\_Year»  
Place of diagnosis: «Diagnosis\_State»

**Death**

According to our records this patient has reportedly died due to the following cause

Date of death:  
Place of death:

**From your own knowledge or medical records please complete (tick) the statements below.**

1. This person has had «Diagnosed\_Condition» Yes  No  Not able to say   
If the person has not had «Diagnosed\_Condition» but has had a similar condition or one that may be confused with it, please specify the condition:.....
2. This person has died Yes  No  Not able to say   
If possible please specify the cause of death .....

**3. LEUKAEMIA AND SPINA BIFIDA**

**If you are confirming leukaemia or spina bifida in a veteran or their child, please indicate the type below.**

Acute lymphatic leukaemia  Acute myeloid leukaemia  Type unknown   
Chronic lymphatic leukaemia  Chronic myeloid leukaemia

Spina bifida

- present in clinically significant form
- present but not in a clinically significant form (e.g. occulta type, incidental finding)

**4. COMPLETING DOCTOR'S SIGNATURE AND OTHER INFORMATION**

Signature .....  
Date ...../...../.....



Name .....  
(if not the same as above)

Address.....

State ..... Post code .....  
Ph. (.....) .....

**FREECALL HELPLINE 1800 236 166**  
Dr Paul Magnus, Mr Phil Trickett

**PLEASE RETURN BY 27<sup>th</sup> August  
TO THE REPLY PAID ADDRESS  
OR VIA FAX (02) 62441191**

**REPLY PAID 1297  
LOCKED BAG 8550  
AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
CANBERRA ACT 2601**

## INFORMATION SHEET - VIETNAM VETERANS VALIDATION STUDY

**PLEASE READ THIS SHEET CAREFULLY BEFORE YOU COMPLETE THE FORM(S)**

Enclosed with this letter you will have received a yellow survey form(s). This means that your father indicated in the Vietnam Veterans Health Survey that you have had one of the health problems now being studied.

Participation in this validation stage of the study is voluntary, but it is **vital** to get an accurate picture, and this needs your participation. If you decide to participate, it would help us most if you give your full consent by ticking **Yes** where relevant and completing all details on each form. However, other options are provided.

We are aware that we are asking you about issues that can be deeply personal and bring up painful memories. Your participation is much appreciated. We have done all we can to ensure that the details on your form(s) are correct. If you find any incorrect or missing information would you please accept our apologies and let us know the correct details.

### **Completing the survey forms**

The survey forms request information about your health conditions. They also seek your consent to confirm these conditions with a doctor, hospital or disease register. If you have any documentation which might prove helpful in confirming these conditions it would be helpful if you enclose a copy with your reply.

### **Confidentiality**

All survey details will be held at the Australian Institute of Health and Welfare (AIHW) and treated with the strictest confidentiality. The AIHW is bound by strict confidentiality provisions in its Act (1987) and the privacy principles in the Privacy Act (1988). The study is monitored by the AIHW's Ethics Committee. You can be assured that only de-identified information will be disclosed as a result of this study.

### **Need more help?**

If you would like more information about the study or assistance completing the form, you are welcome to call the **FREECALL HELPLINE - 1800 236 166**.

We will be very happy to answer your questions **Monday to Friday 9am-7pm (EST)**.

For calls outside these hours, leave your name and phone number and we will return your call.

Please return your consent form in the enclosed reply paid envelope by **February 12** to:

**REPLY PAID 1297**

**Vietnam Veterans Validation Study  
Australian Institute of Health and Welfare  
LOCKED BAG 8550  
CANBERRA ACT 2601**



**THANK YOU FOR YOUR PARTICIPATION**

# Appendix 15 Telephone protocol for veterans not reporting all conditions from the Morbidity Study

## Telephone prompting protocol

*[Use the list generated for each telephonist, phone between 5.30 p.m. and 8.30 p.m. only.*

*Extract the veteran or child's record from the database prior to calling.*

*Ask for the veteran/child by name and arrange to call back if they are unavailable.]*

Hello, I'm *[Interviewer's full name]* from the Australian Institute of Health and Welfare. I am ringing in regards to the **Vietnam Veterans Validation Study** which you participated in earlier this year.

We are nearing the end of our study and we have discovered that in some records there is a discrepancy between the original data supplied to us from the Morbidity Study and that you supplied for this study. Do you have a few minutes to go through your record?

[You have supplied us with information that matches what we have received from the Morbidity Study. However,] it appears from the Morbidity Study that one or more of your children have also suffered from *[Insert conditions]* of which we have no record. Is this the case, or is our information incorrect?

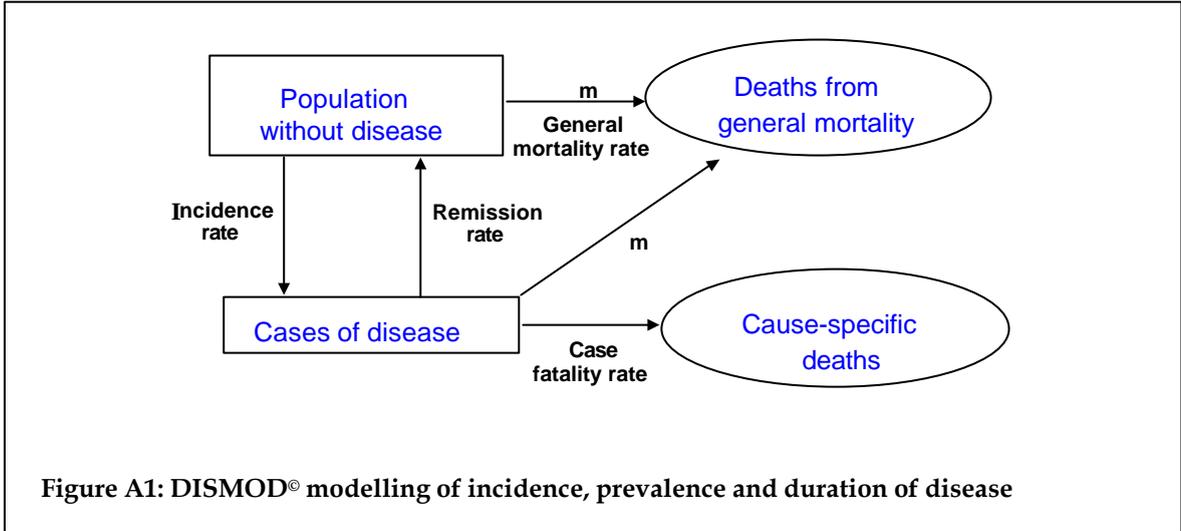
*[Establish whether the condition exists in the veteran's children. If it doesn't mark 'no' on the form provided. If the condition exists in a child under the age of 17 then explain that a form will be sent to the veteran for his consent to validate. If the condition exists in a child over the age of 17, ask for permission to send a form to the child and ask for the child's address and phone number.]*

Thank you for your help. [We will send those forms out first thing tomorrow.]

Goodbye.

# Appendix 16 Calculation of the Australian community standard for colorectal cancer

The calculation of the Australian community standard for colorectal cancer was determined by the AIHW from the software program DISMOD<sup>®</sup>. DISMOD<sup>®</sup> was developed by the Burden of Disease Unit at the Centre for Health and Population Studies, Harvard, to assist disease experts to arrive at internally consistent estimates of incidence, duration and case fatality rates for the Global Burden of Disease Study (Murray & Lopez 1996). The underlying model is shown in Figure 1.



The program is based on a multi-state life table and uses various input parameters to derive consistent epidemiological estimates of disease incidence, duration and case fatality. Some of the input parameters are general (such as the age composition of the male or female population and the general mortality risk at each age) and others specific to the disease under consideration (such as instantaneous incidence and remission rates and cause-specific mortality risk). Outputs from the program include estimates of prevalence, average duration (before remission or death) and cause-specific mortality by age.

Incidence and case fatality rates (survival rate) were entered for colorectal cancer along with the age structure of the population in 1988. The incidence rates were derived from the same publication used in the Morbidity Study (DVA 1998a). The prevalence and mortality rates of colorectal cancer were the outputs of the program. Once the mortality rates were consistent with those in the publication used in the Morbidity Study, the total prevalence rate was accepted.

The confidence interval (CI) was then calculated using the methods presented in Holman et al. (1987)

$$CI \text{ approximation} = AS \text{ Rate} \pm 1.96 \times \frac{AS \text{ Rate}}{\sqrt{\text{Number of cases}}}$$

# Appendix 17 ‘Other cancers’ in veterans

Table A2: ‘Other cancers’ in veterans by cancer type

Cancer type	No. of cancers
Adrenal gland	4
Brain	4
Bladder	4
Bone	1
Digestive system	1
Hodgkin’s disease	4
Kidney	4
Mesothelioma	1
Multiple myeloma	7
Pancreas	1
Penis	1
Spinal cord	1
Thyroid gland	4
Thymus	1
Unknown primary site	10
<b>Total</b>	<b>48</b>

## Appendix 18 'Other cancers' in veterans' children

Table A3: 'Other cancers' in veterans' children by cancer type

<b>Cancer type</b>	<b>No. of cancers</b>
Adrenal gland	10
Bladder	2
Breast	1
Bronchus	1
Bone	3
Colorectal	2
Cervix	1
Eye	3
Head or neck	2
Hodgkin's disease	5
Kidney	1
Melanoma of the skin	15
Non-Hodgkin's lymphoma	13
Ovarian cancer	4
Soft tissue sarcoma	3
Stomach	1
Testis	2
Thyroid gland	4
Unknown primary site	28
<b>Total</b>	<b>101</b>

# Appendix 19 Extra body parts in veterans children

Table A4: Extra body parts in veterans' children by number

Extra body part	No. of conditions
Ear	2
Finger	4
Kidney-related	2
Nipple	1
Ribs	2
Toes	3
Ureter	4
Uterus	2
Vertebrae	1
Not stated	17
<b>Total</b>	<b>38</b>

# Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ALL	Acute lymphatic leukaemia
AML	Acute myeloid leukaemia
AVADSC	Australian Veterans and Defence Service Council
CARO	Central Army Records Office
CLL	Chronic lymphatic leukaemia
CML	Chronic myeloid leukaemia
CMR	Congenital Malformations Register
DVA	Commonwealth of Australia Department of Veterans' Affairs
ICD-9	International Classification of Diseases, 9th Revision
MND	Motor neurone disease
MS	Multiple sclerosis
NCSCCH	National Cancer Statistics Clearing House
NDI	National Death Index
NHL	Non-Hodgkin's lymphoma
NMSC	Non-melanocytic skin cancer
NPSU	National Perinatal Statistics Unit
PTSD	Post-traumatic stress disorder
RSL	Returned & Services League of Australia Limited
SIDS	Sudden infant death syndrome
VVAA	Vietnam Veterans' Association of Australia
VVFA	Vietnam Veterans' Federation of Australia
WHO	World Health Organization

# Glossary

**Absent body part:** A congenital malformation characterised by total or partial absence or severe stunting of skeletal structures of the limbs. In this study it refers to the total or partial absence of the arm, fingers, hand, radius, femur, foot, leg and toes.

**Acute lymphatic leukaemia (ALL):** A cancer of the white blood cells where the disease has a rapid onset and the cancer cells are of the lymphocyte type.

**Acute myeloid leukaemia (AML):** An acute onset cancer of the white blood cells where the cancer arises in the bone marrow.

**Anaemia:** A reduction in normal levels of haemoglobin, the protein in red blood cells which carries oxygen. Has many causes, including bleeding and processes that damage the red blood cells or reduce their production.

**Anencephaly:** Absence of the cerebrum, cerebellum, and flat bones of the skull in the foetus (born without a brain).

**Basal cell carcinoma:** A skin cancer of cells resembling those of the basal (deepest) layer of the skin. It is locally invasive but rarely metastasises.

**Benign tumour:** A non-malignant growth. It does not invade other tissues or spread to other parts of the body, but can expand to interfere with local healthy structures.

**Cancer of the head and neck:** All malignant cancers of the head and neck area except skin cancers, eye cancers and brain cancers. Includes cancers of the lip, tongue, salivary glands, gum, mouth, tonsils, oesophagus, ears, nasal passage and larynx.

**Cancer of the nervous system:** Malignant tumour of the brain, spinal cord or nerves.

**Cancer:** Describes a range of diseases in which abnormal cells multiply and spread out of control. The main features of a malignant tumour (cancerous growth) are its ability to grow in an uncontrolled way and to invade and spread to other parts of the body (metastasis).

**Crohn's disease:** A chronic inflammation of the intestine. The severity of symptoms can fluctuate but they typically include abdominal pain and can include diarrhoea, fever and weight loss.

**Chronic lymphatic leukaemia (CLL):** A leukaemia where the onset and progression of the disease is usually very gradual and the cancer cells are of the lymphocyte type. This is the most common type of leukaemia in adults over the age of 45.

**Chronic myeloid leukaemia (CML):** A disorder where the multiplication of bone marrow cells is excessive. Maturation of the cells proceeds fairly normally.

**Cirrhosis of the liver:** A condition of the liver representing severe damage with scarring and disturbed structure.

**Cleft lip (harelip):** A congenital cleft (groove) in the upper lip, resulting from a failure of parts of the face to join up during early growth in the womb.

**Cleft palate:** Congenital defect due to failure of parts of the face to join up during growth in the womb resulting in a groove through the palate.

**De-identified information:** Information on an individual, stored in the database or on file, that cannot be linked to the name or address of that individual. The individual can not be identified from any of the data provided.

**Down syndrome:** A congenital disorder with a typical facial appearance, mental retardation and often other defects. It arises from an extra chromosome (Trisomy 21).

**Encephalitis:** Inflammation of the brain.

**Extra body part:** An extra body part is defined as a significant extra body part where the deformity causes significant impairment or reduced function, requires significant treatment or management to be corrected or poses a significant risk of death.

**Extra condition:** Conditions which arose before the Morbidity Study, not reported by the veteran then but reported in the Validation Study. These conditions are included in the results.

**Hodgkin's disease:** A cancer marked by progressive painless enlargement of lymph nodes throughout the body. A form of lymphoma.

**Hydrocephalus:** 'Water on the brain'. A disorder where the fluid around the brain builds up because of a blockage in its flow.

**Leukaemia:** A group of cancers of the white blood cells. The course of the disease varies with the type of leukaemia.

**Lymphoma:** A cancer of the lymphatic tissues. The two main types of lymphomas are Hodgkin's disease and non-Hodgkin's lymphoma.

**Melanoma of the skin:** A cancer of the pigment (melanin) cells of the skin.

**Mesothelioma:** A cancer of cells similar to those forming the lining of the lungs, heart, the abdominal cavity and its organs.

**Metastasis:** The transfer of a cancer from its original site to other parts of the body.

**Motor neurone disease:** A chronic slowly progressive disease marked by the wasting of muscles and associated with weakness and paralysis.

**Multiple sclerosis:** One of the most common nervous system disorders with symptoms such as weakness or loss of control in the limbs, sudden vision problems or disturbed sensations.

**New condition:** Conditions reported by a veteran and/or his children that have developed since the Morbidity Study. These were diagnosed in 1998 and 1999 and therefore cannot be included in the results.

**New veteran:** A veteran who had not completed the Morbidity Study survey, but came forward to offer their information in the Validation Study. They were validated as per the study methods but their conditions are not included in the results as they are a bias sample.

**Non-Hodgkin's lymphoma (NHL):** A lymphoma which is not of the Hodgkin's type. It results in the enlargement of the lymph nodes and often other more severe symptoms of cancer.

**Non-melanocytic skin cancer:** A type of skin cancer not involving pigment (melanin) cells.

**Not able to be validated:** A condition is considered not able to be validated where the validation source nominated by the respondent cannot be contacted or accessed, or where the validation source indicates they are not able to confirm or deny the existence of the condition. A condition is also considered not able to be validated where no response from the veteran or their child has been received.

**Not validated:** A condition is considered not validated where information provided from the validation source indicates clearly that the specified condition does not or has not existed in the respondent to the best of their knowledge. The category also applies where the respondent and their condition does not exist on a disease or death register or where a respondent clearly indicates they do not have the specified condition.

**Scoliosis:** A lateral (sideways) curvature of the spine.

**Soft tissue sarcoma:** A cancer of the soft tissues of the body, including tendons, muscles and fat tissue.

**Solar keratosis:** Skin growths which are caused by cumulative sun exposure and are pre-malignant.

**Spina bifida – maxima:** A congenital defect where the covering of the spinal cord protrudes out of an incompletely closed spinal column, usually in the lower part of the back.

**Spina bifida – occulta:** A defect in the spinal column where there is no protrusion in the covering of the spinal cord. It usually has no symptoms and is not clinically significant.

**Squamous cell carcinoma:** A cancer originating in the squamous cells of the skin.

**Thymus:** The central lymphoid organ which controls many aspects of immunologic activity.

**Tracheo-oesophageal fistula:** Abnormal congenital or acquired communication between the trachea and the oesophagus.

**Validated:** A condition is considered validated if sufficient information has been provided by the validation source to confirm that the condition currently exists or has existed at some time.

**Validation source:** The provider of medical information that confirms the existence of a condition. In this study the validation sources include the doctors nominated by the veteran or his children, a disease or death register or medical documents.

**Wilm's tumour:** A malignant tumour of the kidney, usually affecting infants and children.



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