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

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

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 NCSCH 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

Validation source	Validated	Not validated	Not able to be validated
Clinician	63	16	12
No clinician response	—	—	15
Documentation	11	1	—
NCSCH	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
Total	**100**	**100**	**100**

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

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

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.