

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

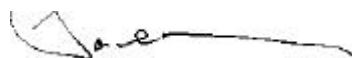
I am writing to you as part of an important study into the health of Australian Vietnam Veterans. Self-reporting by veterans in the Vietnam Veterans' Health Study (1997) suggests excess rates of certain serious conditions. The Department of Veterans' Affairs has commissioned the Australian Institute 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 **18th 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.

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 27th 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.

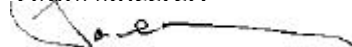
We would appreciate it if you could complete the enclosed form and return it by the **16th July**. We may contact you by telephone in the next few days in case you have any queries, or you may contact me through the freecall Help line **1800 236 166**.

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

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GPO Box 570
Canberra ACT 2601

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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

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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.

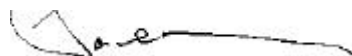
Could you please contact your doctor and arrange for him/her to complete the enclosed validation form(s). We ask that you or your doctor return the form(s) by the **30th April** to the address or fax number on the form.

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

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Phone 02 6244 1000
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<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»

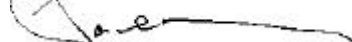
I am writing to you as part of an important study into the health of Australian Vietnam Veterans. Self-reporting by veterans in the Vietnam Veterans' Health Study (1997) suggests excess rates of certain serious conditions. The Department of Veterans' Affairs has commissioned the Australian Institute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

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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.

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Yours sincerely,



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Medical Adviser
9 April 1999

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Study ID number:

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4. COMPLETING DOCTOR'S SIGNATURE AND OTHER INFORMATION

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



Name
(if not the same as above)

Address.....

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

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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?

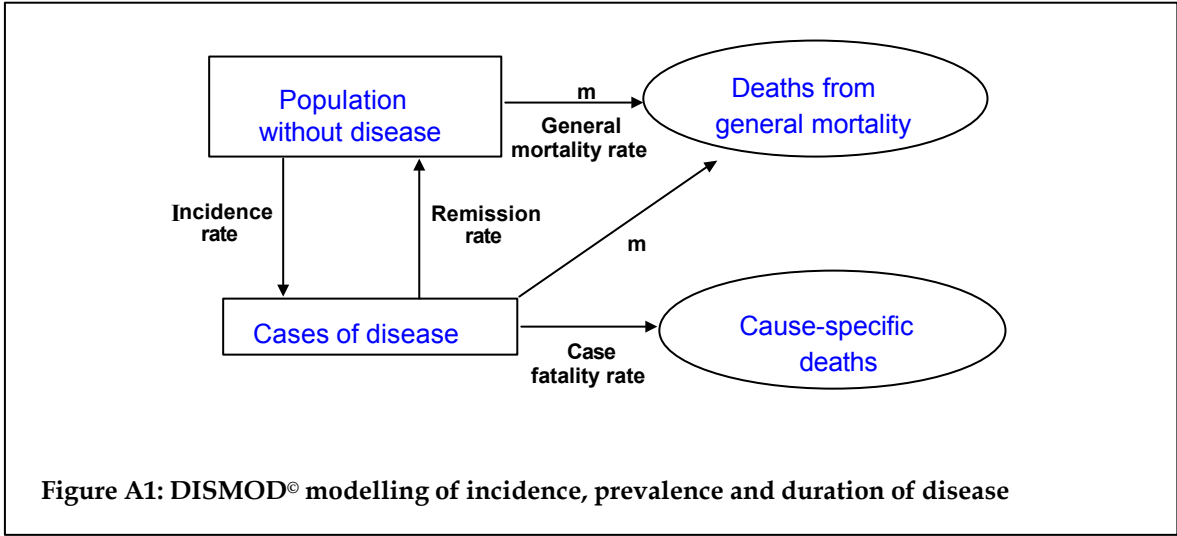
[Establish whether the condition exists in the veteran's children. If it doesn't mark 'no' on the form provided. If the condition exists in a child under the age of 17 then explain that a form will be sent to the veteran for his consent to validate. If the condition exists in a child over the age of 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[®]. DISMOD[®] 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
Total	48

Appendix 18 ‘Other cancers’ in veterans’ children

Table A3: ‘Other cancers’ in veterans’ children by cancer type

Cancer type	No. of cancers
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
Total	101

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
Total	38