

Appendixes

Appendix 1	Australian Institute of Health and Welfare project team
Appendix 2	Study Advisory Committee
Appendix 3	Medical Advisory Panel
Appendix 4	Initial mail-out package to veterans
Appendix 5	First reminder mail-out package to veterans
Appendix 6	Second reminder mail-out package to veterans
Appendix 7	Apology letter to veterans
Appendix 8	Initial mail-out package to veterans' children
Appendix 9	Reminder mail-out package to veterans' children
Appendix 10	Telephone prompting protocol for veterans and children
Appendix 11	Doctor mail-out package
Appendix 12	Reminder mail-out package to doctors
Appendix 13	Telephone prompting protocol for medical practitioners
Appendix 14	Mail-out packages for self-validation by veterans and veterans' children with help from their doctors
Appendix 15	Telephone protocol for veterans not reporting all conditions from the Morbidity Study
Appendix 16	
	Calculation of the Australian community standard for colorectal cancer
Appendix 17	'Other cancers' in veterans
Appendix 18	'Other cancers' in veterans' children
Appendix 19	Extra body parts in veterans' children

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.

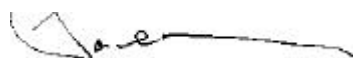
The initial results indicated that certain problems may occur more often among Vietnam veterans than in the general population. These problems include multiple sclerosis, motor neurone disease and cancers and, in veterans' children, birth defects, cancers and deaths from a range of causes.

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

According to our records you indicated in the 1997 Vietnam Veterans Health Study that your child was diagnosed with a medical condition and/or has died. To carry out this validation study, we need some details about your child. Please provide an information you can give in response to the following questions.

SECTION 1

PLEASE PRINT CLEARLY

Child's surname

Child's date of birth/...../19.....
 Day Month Year

Child's given names

Child's mother's date of birth/...../19..... or her age at the
 Day Month Year child's birth ...

Sex Male Female

(Please tick) Name of the hospital where your child was born

If your child was diagnosed with one of the conditions below, indicate which ones by ticking the box. You may tick more than one box. If your child has died, please indicate the cause of death by ticking the box or writing in the space provided.

Condition	Has your child been diagnosed with this condition? (Please tick if Yes)	When was it diagnosed? (Month/Year)	Where did you live when the condition was diagnosed? (Postcode/State)	Did this condition cause your child's death? (Please tick if Yes)
Spina bifida	<input type="checkbox"/>/.....	<input type="checkbox"/>
Anencephaly	<input type="checkbox"/>/.....	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>/.....	<input type="checkbox"/>
Tacheosophageal fistula	<input type="checkbox"/>/.....	<input type="checkbox"/>
Cleft lip or palate	<input type="checkbox"/>/.....	<input type="checkbox"/>
Absent/Extra body parts	<input type="checkbox"/>/.....	<input type="checkbox"/>
Leukaemia	<input type="checkbox"/>/.....	<input type="checkbox"/>
Wilm's tumour	<input type="checkbox"/>/.....	<input type="checkbox"/>
Cancer of the nervous system	<input type="checkbox"/>/.....	<input type="checkbox"/>
Other cancer	<input type="checkbox"/>/.....	<input type="checkbox"/>
Other cause of death			

If your child does not have any of these conditions and has not died, please tick here and go to section 2-4.

If you have medical documentation which may help us with this study it would be helpful if you enclose a copy with your reply. DO NOT SEND ORIGINALS

IMPORTANT INSTRUCTIONS

To enable us to confirm your child's medical condition or cause of death through medical records, we need **your consent (Section 2)** or that of **your child (Section 3)**. Please choose only **one** section.

Please complete Section 2 (see below) if

- your child is under seventeen; OR
- your child has died; OR
- your child has an intellectual disability and you are the guardian

In all other cases, go to section 3 (back of page) ⇒

SECTION 2

1a. To enable us to confirm this condition or death through medical records, will you give us permission to obtain medical information about your child (relating **only** to the above condition(s) or cause of death) from a medical practitioner or hospital or consult disease/death registers?
(Please tick)

YES NO
 If Yes, go to 2; If No, go to 1b

1b. If **No**, would you prefer to contact the doctor yourself? In this case we will send you the medical form which you will need to either send or take to an appropriate doctor as soon as possible.
(Please tick)

YES NO
 If Yes, go to 2; If No, go to 1b

2. For each of the conditions you ticked in Section 1, please indicate an appropriate medical practitioner/practice/hospital with information about your child's condition. (Note: if you cannot give us the details, please give us any information that may help our follow up.) **Other wise, go to 3.**

Doctor's name/practice/hospital

Doctor's phone number ()

Doctor's address Street

Suburb State Postcode

If you need additional space please attach a separate sheet

3. Complete only if your child has died. Otherwise, go to 4.

Date of death/...../19.... Place of death (State/Territory) Postcode

Day Month Year

(if unsure of the date, you can indicate the approximate period)

Please indicate an appropriate medical practitioner/practice/hospital with information about your child's condition.
(Note: if you cannot give us the details, please give us any information that may help our follow up.)

Doctor's name/practice/hospital

Doctor's phone number ()

Doctor's address Street

Suburb State Postcode

4. 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

5. Please print your name and sign below

Name:

Please return to the address below by DECEMBER 11

Signature:

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

SECTION 3

Please complete this section only if

- your child is seventeen or older and does **not** have an intellectual disability: **OR**
- your child is seventeen or older **and** has an intellectual disability **and** you are **not** the guardian (in this case consent needs to be given by the guardian)

1. If your child is seventeen or older, we are required to contact him/her or their guardian directly to ask for permission to obtain medical information. To enable us to do this, could you give us the following details. **PLEASE PRINT CLEARLY**

Your child's address Street

Suburb State Postcode.....

Your child's phone number () Home/Work

2. If your child has an intellectual disability, and you are not the guardian, please indicate the name/details of the guardian.

Guardian's name

Guardian's address Street

Suburb State Postcode.....

Guardian's phone number ()

PLEASE SEND THIS FORM IN THE REPLY PAID ENVELOPE BY DECEMBER 11 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



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 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.

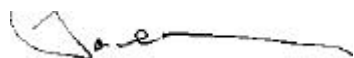
According to our records you, along with approximately 7,000 other Vietnam veterans, were sent a survey package in October. At the time of writing we have received a significant number of responses, however we have not yet received your reply. **If you have recently returned your form(s), thank you for 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 4th 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,

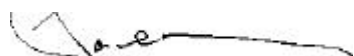
In 1997 you took part in the Vietnam Veterans Health Study which showed that certain health problems may occur more often among Vietnam veterans and their children than in the general population.

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.



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

According to our records you indicated in the 1997 Vietnam Veterans Health Study that your child was diagnosed with a medical condition and/or has died. To carry out this validation study, we need some details about your child. Please provide an information you can give in response to the following questions.

SECTION 1

PLEASE PRINT CLEARLY

Child's surname

Child's date of birth/...../19.....
 Day Month Year

Child's given names

Child's mother's date of birth/...../19..... or her age at the child's birth ...
 Day Month Year

Sex Male Female (Please tick) Name of the hospital where your child was born

If your child was diagnosed with one of the conditions below, indicate which ones by ticking the box. You may tick more than one box. If your child has died, please indicate the cause of death by ticking the box or writing in the space provided.

Condition	Has your child been diagnosed with this condition? (Please tick if Yes)	When was it diagnosed? (Month/Year)	Where did you live when the condition was diagnosed? (Postcode/State)	Did this condition cause your child's death? (Please tick if Yes)
Spina bifida	<input type="checkbox"/>/.....	<input type="checkbox"/>
Anencephaly	<input type="checkbox"/>/.....	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>/.....	<input type="checkbox"/>
Tacheosophageal fistula	<input type="checkbox"/>/.....	<input type="checkbox"/>
Cleft lip or palate	<input type="checkbox"/>/.....	<input type="checkbox"/>
Absent/Extra body parts	<input type="checkbox"/>/.....	<input type="checkbox"/>
Leukaemia	<input type="checkbox"/>/.....	<input type="checkbox"/>
Wilm's tumour	<input type="checkbox"/>/.....	<input type="checkbox"/>
Cancer of the nervous system	<input type="checkbox"/>/.....	<input type="checkbox"/>
Other cancer	<input type="checkbox"/>/.....	<input type="checkbox"/>
Other cause of death			

If your child does not have any of these conditions and has not died, please tick here and go to section 2-4.

If you have medical documentation which may help us with this study it would be helpful if you enclose a copy with your reply. DO NOT SEND ORIGINALS

IMPORTANT INSTRUCTIONS

To enable us to confirm your child's medical condition or cause of death through medical records, we need **your consent (Section 2)** or that of **your child (Section 3)**. Please choose only **one** section.

Please complete Section 2 (see below) if

- your child is under seventeen; OR
- your child has died; OR
- your child has an intellectual disability and you are the guardian

In all other cases, go to section 3 (back of page) ⇒

SECTION 2

1a. To enable us to confirm this condition or death through medical records, will you give us permission to obtain medical information about your child (relating **only** to the above condition(s) or cause of death) from a medical practitioner or hospital or consult disease/death registers?
(Please tick)

YES NO
 If Yes, go to 2; If No, go to 1b

1b. If **No**, would you prefer to contact the doctor yourself? In this case we will send you the medical form which you will need to either send or take to an appropriate doctor as soon as possible.
(Please tick)

YES NO
 If Yes, go to 2; If No, go to 1b

2. For each of the conditions you ticked in Section 1, please indicate an appropriate medical practitioner/practice/hospital with information about your child's condition. (Note: if you cannot give us the details, please give us any information that may help our follow up.) **Other wise, go to 3.**

Doctor's name/practice/hospital

Doctor's phone number ()

Doctor's address Street

SuburbStatePostcode

If you need additional space please attach a separate sheet

3. Complete only if your child has died. Otherwise, go to 4.

Date of death/...../19.... Place of death (State/Territory) Postcode
Day Month Year

(if unsure of the date, you can indicate the approximate period)

Please indicate an appropriate medical practitioner/practice/hospital with information about your child's condition.
(Note: if you cannot give us the details, please give us any information that may help our follow up.)

Doctor's name/practice/hospital

Doctor's phone number ()

Doctor's address Street

Suburb State Postcode

4. 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

5. Please print your name and sign below

Name: Please return to the address below by **DECEMBER 11**

Signature:

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

SECTION 3

Please complete this section only if

- your child is seventeen or older and does **not** have an intellectual disability: **OR**
- your child is seventeen or older **and** has an intellectual disability **and** you are **not** the guardian (in this case consent needs to be given by the guardian)

1. If your child is seventeen or older, we are required to contact him/her or their guardian directly to ask for permission to obtain medical information. To enable us to do this, could you give us the following details. **PLEASE PRINT CLEARLY**

Your child's address Street
Suburb State Postcode.....

Your child's phone number () Home/Work

2. If your child has an intellectual disability, and you are not the guardian, please indicate the name/details of the guardian.

Guardian's name

Guardian's address Street

Suburb State Postcode.....

Guardian's phone number ()

PLEASE SEND THIS FORM IN THE REPLY PAID ENVELOPE BY DECEMBER 11 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.

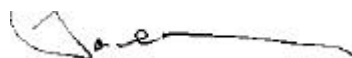
Please accept our sincere apologies and be assured that we have taken corrective action for all veterans affected by the error. We would appreciate it if you would complete and return the form(s) as soon as possible. If you find you now have more forms than you need, you can return any extra forms empty. 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 24th 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.

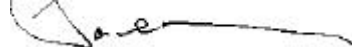
The initial results of the study indicated that certain problems may occur more often among Vietnam veterans and their families than in the general population. These problems include multiple sclerosis, motor neurone disease and cancers in veterans themselves and, in veterans' children, birth defects,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

<p>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)</p>	<p>YES <input type="checkbox"/></p> <p>If Yes, go to 3</p>	<p>NO <input type="checkbox"/></p> <p>If No, go to 2b</p>
--	--	---

<p>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)</p>	<p>YES <input type="checkbox"/></p> <p>If Yes, go to 4</p>	<p>NO <input type="checkbox"/></p> <p>If No, go to 4</p>
---	--	--

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..... StatePostcode.....

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

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

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.

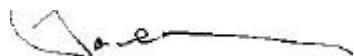
We cannot go any further with this study unless we receive your permission to confirm these reported conditions.

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

<p>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)</p>	<p>YES <input type="checkbox"/></p> <p>If Yes, go to 3</p>	<p>NO <input type="checkbox"/></p> <p>If No, go to 2b</p>
--	--	---

<p>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)</p>	<p>YES <input type="checkbox"/></p> <p>If Yes, go to 4</p>	<p>NO <input type="checkbox"/></p> <p>If No, go to 4</p>
---	--	--

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..... StatePostcode.....

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

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

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
CANNBERRA 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.]