

BY THE COMPTROLLER GENERAL

Report To The Congress

OF THE UNITED STATES

VA's Agent Orange Examination Program: Actions Needed To More Effectively Address Veterans' Health Concerns

Although the Veterans Administration's (VA's) agent orange examinations were more thorough than veterans perceived, GAO generally confirmed veterans' complaints that

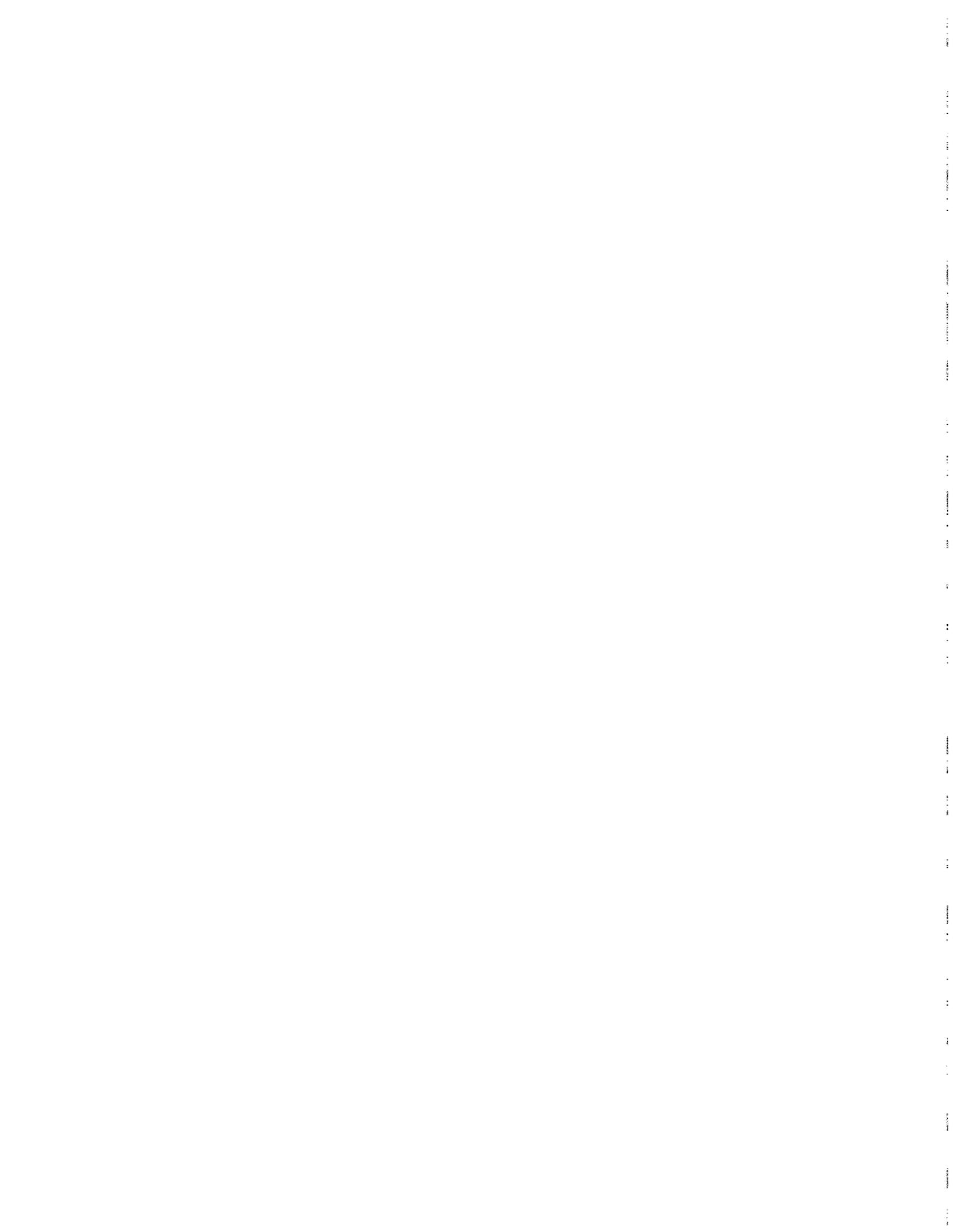
- the examinations were not thoroughly conducted,
- VA provided veterans little or no information on agent orange or their health, and
- VA personnel were not well informed about the examination program.

VA could reduce dissatisfaction and concerns by providing veterans timely and thorough examinations and adequate information about agent orange and their health.

GAO makes several recommendations to improve program management and increase veterans' awareness of the agent orange-related services VA offers.



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COMPTROLLER GENERAL OF THE UNITED STATES
WASHINGTON D.C. 20548

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To the President of the Senate and the
Speaker of the House of Representatives

This report, requested by Congressman Thomas Downey and Senator John Heinz, discusses opportunities for the Veterans Administration (VA) to improve its agent orange examination program and to increase veterans' awareness of VA's agent orange-related services. The report also discusses the need for the Congress to consider whether the retroactive compensation period for agent orange-related disability claims should be extended.

Copies of this report are being sent to the Administrator of Veterans Affairs; the Director, Office of Management and Budget; and other interested parties.

A handwritten signature in cursive script that reads "Shelton J. Fowler".

Acting Comptroller General
of the United States

D I G E S T

Although the Veterans Administration's (VA's) agent orange examination program was intended as a response to Vietnam veterans' concerns about the potential adverse health effects of exposure to agent orange, veterans are generally dissatisfied with VA's efforts. Congressman Thomas Downey and Senator John Heinz requested that GAO determine the effectiveness of VA's efforts to assist veterans concerned about agent orange.

Since 1978, VA has provided examinations to over 89,000 Vietnam veterans. Although the examinations were more thorough than veterans perceived, GAO's evaluation of the examination programs at 14 of VA's 178 medical facilities generally confirmed veterans' complaints.

CLOSER MONITORING OF PROGRAM
COULD REDUCE DISSATISFACTION

VA could reduce dissatisfaction and concerns by providing veterans timely and thorough examinations and adequate information about agent orange and their health.

About 55 percent of the 891 veterans responding to GAO's questionnaire were dissatisfied with their agent orange examination. Generally, veterans complained that

- their examinations were not thorough,
- VA provided them little or no information on the potential health effects of agent orange exposure,
- VA personnel did not show enough interest in their health, and
- they did not get an examination as soon as they wanted. (See pp. 5 and 6.)

Comparison of examination records with questionnaire responses for a random sample of 96 respondents, however, showed that the examinations were more thorough than the veterans perceived. (See pp. 6 to 8.)

Nonetheless, only 1 of the 14 facilities GAO visited was adequately following up on the health problems reported by veterans. Furthermore, only about 10 percent of the examination records documented a complete medical history, and only about 36 percent indicated that the physical examination covered all required body parts and systems. (See pp. 8 to 11.)

Two factors which may have contributed to the examinations' lack of thoroughness were the (1) poor design of the examination forms and (2) examining physicians' lack of familiarity with agent orange.

The medical history and physical examination forms did not list all factors to be covered including some health problems veterans have attributed to agent orange. (See pp. 11 and 12.)

Examining physicians at four facilities GAO visited were not familiar with VA circulars describing the agent orange program or the body systems on which the examination should focus. (See pp. 13 and 14.)

Environmental physicians at 6 of the 14 facilities GAO visited believed the examination program was of little or no use because no health effects of exposure to agent orange, except the skin condition chloracne, have been proven. (See pp. 14 and 15.)

VA's Office of Environmental Medicine had no program for monitoring the quality of agent orange examinations. (See pp. 15 and 16.)

VA SHOULD DISCONTINUE COMPUTERIZED AGENT ORANGE REGISTRY

VA's computerized agent orange registry does not contain specific diagnoses of the health problems found in Vietnam veterans. As a result, it cannot be used to determine if the veterans

are experiencing an unusual incidence of chloracne or other skin conditions or to show the types or locations of tumors or types of birth defects in their children. (See pp. 23 and 24.)

VA has not included veterans' addresses in the registry. Thus, the registry is not meeting its two primary objectives--providing information on health problems experienced by Vietnam veterans and facilitating followup with veterans if necessary at a later time. (See pp. 24 and 25.)

VA's Inspector General identified extensive coding errors and duplicate records in the registry, which compromised its value and integrity and resulted in incorrect statistics. However, VA had not corrected the data or assessed the reliability of other data in the registry. (See pp. 25 and 26.)

Although the registry's deficiencies could be corrected, the corrections would be costly and the data still could not be used as a basis for scientifically valid conclusions about veterans' health. Discontinuing the registry but maintaining a list of veterans who have had agent orange examinations could save almost \$1 million a year in administrative staff and computer costs. (See pp. 27 and 28.)

VA SHOULD DO MORE TO ALLEVIATE VETERANS' CONCERNS

Most veterans responding to GAO's questionnaire sought agent orange examinations because they were concerned that health problems, such as chloracne, cancer, and birth defects, may be caused by exposure to agent orange. Many veterans' dissatisfaction with what VA did for them appears to have resulted, in part, from a lack of understanding of the examination's limitations. (See pp. 30 and 31.)

VA could alleviate concerns by providing information on the kinds of skin problems, tumors, and birth defects identified in agent orange examinations. (See pp. 32 to 35.)

For example, VA could tell veterans that dermatologists at VA medical facilities have reported seeing only common skin problems, and that the Armed Forces Institute of Pathology has found few

unusual tumors in tissue samples taken from Vietnam veterans. VA could also alleviate concerns by (1) informing veterans of the limitations of the agent orange examination, (2) providing examination results to veterans who have not received them, and (3) providing veterans available information on agent orange's potential for causing birth defects.

VA OUTREACH EFFORTS NOT EFFECTIVE

Agent orange informational materials prepared by VA were not reaching all veterans concerned about agent orange because VA had not effectively advised veterans of their availability. The lack of information provided by VA was the greatest source of dissatisfaction among veterans responding to GAO's questionnaire.

Although VA has prepared informational materials on agent orange, veterans could generally obtain these materials only at a VA medical facility, regional office, or outreach center. Moreover, when contacted by telephone most VA medical facilities did not (1) inform callers that the pamphlet was available at the facility, (2) offer to send it to callers, or (3) mention that they showed VA's agent orange film in their outpatient clinics. (See pp. 41 and 42.)

In contrast, three States and one VA medical center conducted outreach efforts, including public service announcements, which identified large numbers of veterans who wanted information about agent orange or an examination. (See pp. 42 to 44.)

DENIAL OF DISABILITY CLAIMS MAY PREVENT RETROACTIVE COMPENSATION

Ongoing epidemiological studies are likely to be the primary source of evidence to show whether disability compensation claims which veterans allege to be agent orange related were service connected. However, according to VA, veterans whose disability claims are eventually proven to be service connected based on the results of these studies would be limited by law to 1 year of retroactive compensation from the date of reconsideration rather than the date the initial claim was filed.

About 93 percent of the 14,236 agent orange-related disability claims filed by veterans as of July 1982 have been denied. Almost half of them were denied not because the claimed disability did not exist, but because there was no evidence in the veterans' service medical records or any other source that the disability was diagnosed or treated during the veterans' service. (See pp. 46 to 49.)

However, in Vietnam the treatment for health problems incurred in the field was generally not recorded in a soldier's service medical records. (See p. 48.)

RECOMMENDATIONS TO THE ADMINISTRATOR OF VETERANS AFFAIRS

GAO is making several recommendations to the Administrator to insure that veterans receive timely and thorough examinations and information about agent orange and their health. (See pp. 17, 28, 35, and 44.)

MATTERS FOR CONSIDERATION BY THE CONGRESS

The Congress should consider whether 38 U.S.C. 3010(g) should be amended to extend the retroactive compensation period for agent orange-related disability claims to the date the claim was filed. (See p. 49.)

AGENCY COMMENTS

While VA agreed with most of GAO's recommendations (see app. V), it offered a number of comments suggesting that GAO used old data and the problems were not as serious as GAO maintained. GAO generally disagrees with VA's assessment. VA offers little evidence to suggest that the deficiencies GAO identified have been corrected. GAO believes that action is needed to improve the agent orange examination program. (See pp. 17, 28, 36, 44, and 49.)

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ABBREVIATIONS

GAO	General Accounting Office
VA	Veterans Administration

CHAPTER 1

INTRODUCTION

Congressman Thomas Downey and Senator John Heinz requested that we review the Veterans Administration's (VA's) efforts to assist veterans concerned about the possible adverse health effects of agent orange and its toxic contaminant dioxin. 1/ Specifically, we were asked to determine

- whether VA medical facilities were adequately implementing herbicide screening procedures,
- whether appropriate tests were administered,
- what agent orange-related training was provided VA staff,
- whether VA had allocated adequate funds for the herbicide screening program,
- what VA was doing with the information obtained from examinations,
- why VA had not attempted an outreach program, and
- whether VA was equitably adjudicating agent orange disability compensation claims.

PREVIOUS GAO REPORTS ON AGENT ORANGE

This is our fourth report on agent orange and other chemicals used in Vietnam. The first two reports (CED-78-158, Aug. 16, 1978, and CED-79-22, Apr. 6, 1979) 2/ identified the need to (1) study possible long-term health effects of herbicide exposure on military personnel in Vietnam, (2) obtain information from military records pertaining to a veteran's possible exposure to herbicides in adjudicating herbicide-related compensation claims, and (3) encourage veterans concerned about agent orange to contact VA medical facilities. The third report (FPCD-80-23, Nov. 16, 1979) 3/

1/Agent orange, a mixture of 2,4-D and 2,4,5-T, was the most widely used herbicide in Vietnam. It contained a contaminant, TCDD (2,3,7,8-tetrachlorodibenzo-para-dioxin) which is one of the most toxic chemicals known.

2/Interim letter report on extent of herbicide use in Vietnam and "Health Effects of Exposure to Herbicide Orange in South Vietnam Should Be Resolved."

3/"U.S. Ground Troops in South Vietnam Were in Areas Sprayed With Herbicide Orange."

demonstrated that ground troops were in areas sprayed with agent orange both during and shortly after spraying and that few precautions were taken to prevent exposure.

WHAT IS AN AGENT ORANGE EXAMINATION?

In May 1978, VA's Department of Medicine and Surgery began a program to examine veterans who believed they were exposed to agent orange. Generally, any Vietnam veteran concerned about health problems which may be the result of exposure to herbicides, including agent orange, is eligible for an agent orange examination. The examinations are available at each of VA's 172 medical centers and 6 independent outpatient clinics. According to VA, over 89,000 veterans had been examined as of April 30, 1982.

Each VA medical facility designated a physician (known as the environmental physician) to be responsible for the examination and followup of veterans claiming herbicide exposure. In April 1980, the Office of Special Assistant to the Chief Medical Director for Environmental Medicine was established to oversee the agent orange program at VA medical facilities. In February 1982, VA established the Agent Orange Research and Education Office under the Deputy Administrator to coordinate all VA agent orange activities.

The agent orange examination consists of four parts:

- An exposure history to determine when, where, and how the veteran was exposed to agent orange or other chemicals before, during, and after service in Vietnam.
- A medical history to document medical problems experienced by the veteran since the time of exposure.
- Laboratory tests, such as a complete blood count, blood chemistries, urinalysis, and a chest X-ray.
- A physical examination of 21 body parts or systems focusing on those commonly affected by toxic chemicals.

Once the veteran's examination is completed, the information gathered is entered into the computerized agent orange registry. The registry is intended to (1) identify veterans concerned about the possible health effects of herbicide exposure, (2) document medical information on their health, and (3) facilitate followup with them if health problems related to herbicide exposure are identified.

PRIORITY GIVEN TREATMENT FOR PROBLEMS THAT MAY HAVE BEEN CAUSED BY AGENT ORANGE

The Veterans' Health Care, Training, and Small Business Loan Act of 1981 (Public Law 97-72, Nov. 3, 1981) authorizes priority health care for Vietnam veterans for disabilities that may have been caused by exposure to agent orange or other herbicides.

Such veterans have a higher priority for outpatient care than non-service-connected veterans and the same priority given to former prisoners of war receiving care for non-service-connected conditions.

FUNDING FOR THE AGENT ORANGE
EXAMINATION PROGRAM

VA estimated that its agent orange activities will cost about \$9.5 million in fiscal year 1982, including

- \$6.6 million for conducting physical examinations and collecting medical information at VA medical facilities;
- \$1.6 million for automated data processing support for the agent orange registry and the epidemiological study;
- \$809,000 for staffing the Office of Environmental Medicine in the Department of Medicine and Surgery and additional staff to provide automated data processing for the epidemiological study mandated by Public Law 96-151; and
- \$516,000 for research on the effects of agent orange, including the epidemiological study.

VA also spent about \$18,000 to publish 500,000 copies of the pamphlet "Worried About Agent Orange?" and \$29,000 to produce the videotape "Agent Orange: A Search for Answers."

VA medical centers, except the Minneapolis medical center, were not allocated funds specifically for the agent orange program, but were advised to operate the program with existing resources. Officials at all VA facilities we visited told us that they had adequate funds to conduct the examination program, but they generally indicated that additional funds would be needed if the number of veterans seeking examinations increased significantly. The Minneapolis medical center received an additional \$130,000 in fiscal year 1980 to respond to the increased demand for examinations caused by a Minnesota outreach program.

OBJECTIVES, SCOPE, AND METHODOLOGY

Our objectives were to determine whether

- VA medical facilities were providing veterans thorough examinations and available information on agent orange,
- veterans were satisfied with the services provided,
- VA was doing enough to alleviate veterans' concerns about the possible health effects of agent orange exposure,

- VA was effectively using the information obtained from the examinations,
- VA had an effective program for providing veterans information about agent orange and VA services, and
- agent orange-related disability compensation claims were being properly adjudicated.

Between August 1980 and October 1982 we

- reviewed the agent orange examination records of a random sample of veterans examined between May 1979 and December 1980 and interviewed program officials at 13 VA medical centers and 1 outpatient clinic;
- interviewed officials from VA, State Veterans Affairs Offices, veterans' service organizations, and scientific researchers;
- sent a questionnaire to a random sample of veterans who had had agent orange examinations during 1980;
- validated a sample of the questionnaire responses by comparing them with the veterans' examination records; and
- conducted a telephone survey of 112 VA medical facilities.

We did not attempt to evaluate the treatment provided to veterans diagnosed as having health problems.

Additional details on the objectives, scope, and methodology of our review are contained in appendixes I, II, and III. Appendix I contains details on our work steps and limitations, appendix II contains details on our questionnaire design and sampling methodology, and appendix III contains a copy of the questionnaire and responses.

Our review was conducted in accordance with generally accepted government auditing standards.

CHAPTER 2

IMPROVEMENTS IN VA'S AGENT

ORANGE EXAMINATION PROGRAM

COULD REDUCE VETERAN DISSATISFACTION

About 55 percent of the veterans responding to our questionnaire were dissatisfied with their agent orange examination. Among the veterans' complaints were that

- their examinations were not thorough,
- VA provided them little or no information on the potential health effects of exposure to agent orange,
- VA personnel did not show enough interest in their health, or
- they did not get an examination as soon as they wanted.

Although the examinations were more thorough than the veterans perceived, our discussions with VA officials at 14 medical facilities and review of about 1,300 randomly selected examination records at those facilities generally confirmed the veterans' complaints. Despite the complaints about its examination program, neither VA's central office nor the individual facilities we visited had established an effective monitoring program to insure that veterans received timely and thorough examinations and adequate information about agent orange and their health status.

VETERANS GENERALLY DISSATISFIED WITH AGENT ORANGE EXAMINATIONS

Veterans responding to our questionnaire frequently complained about the services and information VA provided during their agent orange examinations, the amount of time VA spent on their examinations, the interest VA took in their health, and the inconvenience in obtaining the examination. Of the veterans responding to our questionnaire, about

- 49 percent were dissatisfied with the interest VA personnel took in their health,
- 47 percent were dissatisfied with the thoroughness of the questions VA personnel asked them,
- 49 percent were dissatisfied with the opportunity they were given to ask questions,

- 57 percent were dissatisfied with the completeness of their agent orange examination,
- 80 percent were dissatisfied with the amount of information VA provided them about agent orange,
- 83 percent were dissatisfied with the amount of information they learned from VA about their own exposure to agent orange,
- 57 percent were dissatisfied with the amount of time VA spent on their examinations,
- 21 percent were dissatisfied with the convenience of the examination time and date, and
- 23 percent were dissatisfied with the timeliness of their examinations.

VA's lack of action in providing information about agent orange was the greatest source of veteran dissatisfaction. About 80 percent of the veterans were dissatisfied with the information VA provided--about 60 percent said they were very dissatisfied.

About 55 percent of the veterans responding to our questionnaire reported that VA did not provide them any information about agent orange, even though 75 percent of the veterans told us they asked for such information. Furthermore, responses from veterans who received information from VA indicated that only about

- 61 percent were told what agent orange is,
- 58 percent were told how it was used,
- 33 percent were told what may happen to their health if they were exposed, and
- 23 percent were told what may happen to their children's health if the veteran was exposed.

Veterans also reported they were provided little information about the results of their physical examinations and laboratory tests. About 31 percent of the veterans reported that VA told them nothing about their health, and about 66 percent reported that they did not get their laboratory test results.

EXAMINATIONS MORE THOROUGH
THAN VETERANS PERCEIVE

Although veterans complained that their examinations were not thorough, a comparison of the documentation in veterans' examination records to the questionnaire responses for a random sample of

questionnaire respondents showed that the examinations were more thorough than the veterans perceived.

To determine whether veterans responding to our questionnaire were good observers of the examination provided by VA, we compared the questionnaire responses of 96 randomly selected veterans responding to our questionnaire with their examination records at VA medical facilities. This comparison included the exposure and medical history, physical examination, and laboratory tests.

About 53 percent of the veterans told us that VA had not elicited a complete medical history, and about 12 percent said that VA had asked them no questions about health problems they may have been experiencing. Veterans responding to our questionnaire also reported that VA physicians frequently failed to elicit data on the specific health problems cited by veterans as the reason for seeking an examination. However, in about 2 out of 3 cases in our comparison sample the veteran's examination records indicated that responses had been elicited to medical history questions veterans said they had not been asked. Following are some examples.

- Examination records for 8 of the 17 veterans in our comparison, who reported that they were not asked medical history questions about skin problems, showed that they had been asked about their skin.
- Examination records for 10 of 21 veterans in our comparison, who said they were not asked questions about problems with their nerves, indicated they had been asked about problems with their nerves.
- Examination records for 27 of the 28 veterans in our comparison, who said they were not asked questions about birth defects in their children, indicated that they had been asked about birth defects.
- Examination records for 31 of the 33 veterans in our comparison, who said they were not asked if they had a history of tumors, showed that they had been asked about tumors.

Veterans' perceptions of the thoroughness of their physical examination also differed from the information in their examination records. In about 83 percent of the cases where veterans in our comparison reported that a part of their body was not examined, the examination records showed that it was examined. The following are some examples.

- Examination records for 24 of the 28 veterans in our comparison, who reported that their skin was not examined, showed that the veteran's skin had been examined.

--Examination records for 22 of the 23 veterans in our comparison, who said that their stomach was not examined, showed that their stomach had been examined.

--Examination records for 21 of the 26 veterans in our comparison, who reported that their groin was not examined, indicated that their groin had been examined.

According to our medical advisor, physical examinations are frequently more thorough than patients perceive. For example, a physician can examine for skin conditions visually without the patient realizing his or her skin was examined.

AGENT ORANGE EXAMINATIONS
SHOULD BE MORE THOROUGHLY
CONDUCTED AND DOCUMENTED

Although the examinations were more thorough than the veterans perceived them to be, our review of about 1,300 randomly selected examination records at 14 medical facilities showed that thorough medical histories and physical examinations were not generally documented. This problem was particularly serious when the examination records indicated that the veteran reported a past or present health problem. We reviewed the records to see whether they showed that information had been elicited for required medical history questions and that examination of required body parts and systems had been documented. We credited examining physicians with covering the required medical history questions and examination factors whenever the records contained any documentation that suggested that they were covered.

Two factors which may contribute to the lack of thoroughness with which examinations were conducted and documented are the poor design of the examination forms and the examining physicians' lack of familiarity with information about agent orange.

Examination records lack
details on health problems
reported by veterans

Although VA circulars emphasize the importance of getting additional information on health problems reported by veterans, only one of the facilities we visited, the Wilkes-Barre medical center, thoroughly documented this information. Furthermore, most examination records lacked documentation that a complete medical history was elicited and all body parts and systems were examined.

When a veteran reports a past or present health problem, VA circulars direct the examining physician to determine

- when the symptoms or conditions first occurred,
- the intensity of the symptoms or conditions,
- the degree of physical incapacitation at the time of exposure to agent orange, and
- what treatment had been provided.

Only one of the facilities we visited, the Wilkes-Barre medical center, thoroughly documented information on health problems noted in the veterans' medical history. At the Wadsworth medical center and the New York outpatient clinic, none of the medical records reviewed contained details on the health problems reported by veterans. Although the 1,258 examination records we reviewed identified 1,175 past or present health problems in veterans, information on when the symptoms first appeared and the intensity of the symptoms was documented for only about 55 percent of the health problems. Information on the degree of physical incapacitation and treatment was documented for only about 32 and 30 percent of the health problems, respectively. The table below shows the percentage of times each of the followup questions was documented at each facility we visited.

<u>Medical facility</u>	<u>When symptoms first appeared</u>	<u>Intensity of symptoms</u>	<u>Degree of physical incapacitation</u>	<u>Details of treatment</u>
(percent)				
Augusta, Ga.	65	77	49	11
Birmingham, Ala.	39	55	55	23
Decatur (Atlanta), Ga.	44	45	33	15
Hines, Ill.	69	45	13	24
Minneapolis, Minn. Chicago	59	67	38	48
(Westside), Ill.	63	57	33	25
Long Beach, Calif.	31	88	8	31
Los Angeles (Wadsworth), Calif.	0	0	0	0
New York, N.Y.	1	1	1	1
New York outpatient clinic, N.Y.	0	0	0	0
East Orange, N.J.	71	64	51	26
Northport, N.Y.	53	39	2	34
Pittsburgh (University Drive), Pa.	89	58	40	32
Wilkes-Barre, Pa.	90	100	90	100

In addition to inadequate followup of health problems reported by veterans, a complete medical history was documented in only 122 of the 1,258 histories (about 10 percent) reviewed. An average of only 9 of the 15 medical history questions (about 60 percent) were documented in the examination records.

As shown on page 30, veterans most often sought agent orange examinations because they were experiencing problems with their skin, liver, kidneys, or nerves; had tumors or other growths; or had children with birth defects. However, of the 1,258 medical histories we reviewed,

- 368 (29 percent) contained no indication that the veterans were asked whether they were experiencing skin problems,
- 498 (40 percent) contained no indication that veterans were asked whether they had problems with their nerves,
- 317 (25 percent) and 335 (27 percent) contained no indication that the veterans were asked whether they were experiencing liver- or kidney-related problems, respectively,
- 290 (23 percent) contained no indication that the veterans were asked whether they had children with birth defects, and
- 114 (9 percent) contained no indication that the veterans were asked whether they had experienced any tumors or growths.

Some examining physicians told us that they did not elicit a complete medical history, but relied on the veteran to provide information on health problems. Although VA officials told us that some questions are left blank because physicians do not document both normal and abnormal findings on all questions, officials were unable to determine whether an individual question was not documented because there was no abnormal finding or the information was not elicited.

Although physical examinations were better documented than medical histories, most did not indicate that all required body parts and systems were examined. Of the 1,243 physical examinations 1/ we reviewed, 448 (36 percent) indicated that all required parts of the body and body systems were covered. The average physical examination covered about 81 percent of the required body parts and systems.

1/The remaining 15 examination records we reviewed did not contain a physical examination form.

Individual parts of the body or body systems were documented in from 54 to 96 percent of the examination records. Those least often documented were the prostate and back. Those most often documented were the lungs, abdomen, and cardiovascular system. Although chloracne is a recognized symptom of exposure, 17 percent of the examination records did not indicate that the veteran's skin was examined. (See app. IV for additional information on the documentation of the medical histories and physical examinations.)

The environmental physicians at the facilities we visited generally believed that medical histories and physical examinations were not always documented because

- general medical practice is to record only abnormal findings,
- VA circulars on the agent orange examination program do not require that all factors be documented, and
- the examination forms were not conducive to thorough documentation because the medical history and physical examination sections were in open-ended rather than checklist form.

However, the special assistant to the chief medical director for environmental medicine told us that examination records should include both normal and abnormal findings for all body parts and systems. Further, in the examination records we reviewed examining physicians usually recorded both normal and abnormal examination findings for the body parts and systems they examined.

Examination forms are not designed to gather data on problems veterans attribute to agent orange

The poor design of the examination forms used to record the exposure and medical history and physical examination during an agent orange examination may affect the thoroughness with which the examinations are conducted and documented. Revising the forms to include more specific exposure history questions and checklists for the medical history and physical examination should improve the thoroughness of the examinations.

The exposure history section of the examination is intended to gather information on how and where Vietnam veterans were exposed to agent orange, which can assist in identifying trends or patterns in the health problems they are experiencing. However, over half the veterans VA examined as of December 1981 were not able to specify when, where, and how they were exposed to agent orange. As a result, VA cannot identify veterans who served in a particular area in Vietnam or were exposed to agent orange in a particular way. Such data could be important if the results of epidemiological studies should indicate the need to identify these persons.

We believe VA could elicit a more complete exposure history by using a more detailed questionnaire such as the one used by the Vietnam Veterans of America. VA's exposure questionnaire asks the veteran when and where the exposure occurred, but provides no information on the names of areas in Vietnam where veterans might have been exposed. In contrast, the questionnaire used by the Vietnam Veterans of America contains a detailed herbicide exposure section which asks specific questions on the veterans' jobs in the service, how they might have been exposed, and with what unit and where in Vietnam they served.

More importantly the questionnaire provides the location of major military units and the names of villages, towns, provinces, fire support bases, and landing zones in Vietnam to help veterans remember where they served. We reviewed a random sample of 97 completed questionnaires out of about 2,000 returned to the Vietnam Veterans of America and found that about 72 percent of the respondents were able to provide details on specific locations where they served in Vietnam.

VA circulars direct physicians conducting agent orange examinations to focus on specific body systems commonly affected by toxic chemicals and on symptoms and conditions related to such exposure. However, the medical history and physical examination forms used to gather this information do not list all factors which are supposed to be covered. As a result, details on some health problems veterans have attributed to agent orange are not recorded. In contrast, the standard examination forms used for patients admitted to VA medical centers contain checklists with space for details on specific health problems in each major body system. The checklist includes such common Vietnam veteran complaints as loss of appetite, weight loss, and night sweats.

Physicians at five VA facilities we visited used the standard admissions form or other checklist forms, rather than the agent orange examination form, for recording examinations because they were more detailed and easier for the physician to complete than the open-ended forms provided for agent orange examinations. At one medical center (Birmingham) that had used both forms we noted that the thoroughness of the examination documentation improved after it started using the more detailed form.

Officials at nine of the medical facilities visited suggested that revising the examination forms to include checklists for the medical history and physical examination would facilitate thorough data collection. We believe VA could improve the thoroughness with which agent orange examinations are documented by using its standard examination forms.

Examining physicians need additional data on agent orange

Although the environmental physicians at VA medical facilities have been provided extensive information on agent orange, some physicians conducting examinations at four facilities we visited were not familiar with all the information, and others believed it was not adequate. As a result, some physicians performing agent orange examinations may not have sufficient knowledge of the potential symptoms of dioxin exposure or the objectives of the examination program to insure that all pertinent information on a veteran's health is gathered or to provide concerned veterans with all available information on agent orange.

VA central office has provided material to environmental physicians at VA medical facilities to keep them informed on agent orange-related issues so that they can respond to veterans' questions. These materials include

- VA circulars describing the agent orange examination program and registry,
- VA testimony on agent orange,
- testimony by the National Academy of Sciences and the American Council on Science and Health,
- the pamphlet "Worried About Agent Orange?", and
- the videotape "Agent Orange: A Search for Answers."

Environmental physicians also attended two VA educational conferences designed to instruct personnel on how to conduct an agent orange program. The May 1980 conference included presentations on

- the use of herbicides in Vietnam,
- the toxicity of dioxin in animals and relevance to human health,
- diagnostic indicators of dioxin or herbicide toxicity,
- human health effects following exposure to phenoxy herbicides and dioxin, and
- chloracne recognition and significance.

Although environmental physicians have received extensive information on agent orange and most of them told us that they were available to answer the questions of veterans having agent orange examinations, they did not perform examinations or see all veterans who had examinations at 7 of the 14 facilities we visited.

Generally, environmental physicians provided information on agent orange to the physicians performing the physical examinations.

Examining physicians at eight of the facilities we visited believed, however, that more information on the potential symptoms of exposure to agent orange was needed. Also, examining physicians at four of the VA medical facilities we visited were not familiar with VA circulars describing the agent orange program, the body systems on which the examination should focus, or were not sure of the purpose or usefulness of the information VA circulars instructed them to gather from each examination.

SOME ENVIRONMENTAL PHYSICIANS QUESTION
USEFULNESS OF EXAMINATION PROGRAM

Although many of the VA physicians we spoke with had a positive attitude towards the health problems of Vietnam veterans, about half of the environmental physicians expressed negative attitudes about the agent orange program. Environmental and examining physicians at the 14 VA medical facilities we visited generally believed that the agent orange examination program was useful for providing veterans a thorough evaluation of their current health status, however, environmental physicians at 6 of the facilities told us that the program was of little or no use because (1) there were no proven effects of exposure to agent orange, except chloracne, and (2) most veterans were asymptomatic. Generally, these six physicians believed the program served only to pacify veterans who were exploiting the agent orange issue for personal gain.

At VA's Second Continuing Education Conference on Herbicide Orange in May 1980, the special assistant to the chief medical director for environmental medicine said that:

"I cannot stress too strongly my firm conviction, gained from my involvement in Agent Orange activities, that we must consider problems generated by this defoliant in an open minded and forthright manner. We must view our education, in this regard, as a continuing concern and as a professional responsibility which we accept willingly and with genuine enthusiasm. Increasing our knowledge, however, is only one of our goals. Equally important is the need for each of us to demonstrate our sense of respect, compassion and empathy for Vietnam veterans and their families, many of whom are genuinely and understandably worried about the possible adverse health effects of exposure to Agent Orange. We must strive to instill confidence in the minds of Vietnam veterans that we are knowledgeable and that we do indeed share a genuine concern for their mental and physical well-being. This is our responsibility; it is also our privilege."

However, the attitudes of some of the environmental physicians at the medical facilities we visited raised serious questions about their concern for Vietnam veterans worried about the possible effects of agent orange.

FURTHER ACTION NEEDED TO REDUCE EXAMINATION BACKLOGS

Although VA has made progress in reducing backlogs of agent orange examinations, many facilities still require the veteran to wait over a month for an examination. In August 1980, almost 4,000 veterans were waiting for agent orange examinations. In November 1981, the VA central office began monitoring examination backlogs to insure that veterans received timely examinations. By May 31, 1982, VA had reduced the backlog to about 1,650 veterans. However, four facilities (Beckley, Birmingham, Martinez, and Lebanon) had backlogs of between 40 and 50 examinations, and the Anchorage facility had a backlog of 135 examinations.

Based on the number of examinations performed in May 1982, 54 (about 31 percent) of 172 VA medical facilities had more than a 1-month backlog of examinations pending at the end of the month. For example, the Anchorage medical facility performed only 8 examinations during May 1982, but reported a backlog of 135 examinations pending as of May 31, 1982. At the rate of eight examinations a month, it will take veterans up to 17 months to get an examination. Similarly, the Birmingham medical center performed only 10 examinations in May 1982, but had a backlog of 42 examinations at the end of the month. At the rate of 10 examinations a month, veterans will have to wait about 4 months for an examination.

Another factor contributing to veterans' dissatisfaction was the requirement at some VA facilities that veterans make two visits to complete the examination. While this approach has the benefit of allowing laboratory tests to be performed during the initial visit so that the physician can discuss the results on the veteran's second visit, some veterans told us that it was inconvenient for them to return for the second visit. Some veterans said that they had to travel great distances to get to the VA medical facility or that they could not take time off from work on 2 days to complete the examination. Twenty-four VA medical facilities told us that they require the veteran to make two visits to the facility to complete the examination.

VA LACKS AN EFFECTIVE MONITORING PROGRAM

Although VA's Office of Environmental Medicine was established, in part, to oversee the implementation of the agent orange program at VA medical facilities, it had no program for monitoring the quality of care provided veterans obtaining agent orange examinations. Furthermore, environmental physicians were not generally

monitoring the examinations to insure that they were thorough and that veterans with health problems received followup care. None of the facilities were evaluating the examination program as part of their internal review.

In 1980, VA sent a patient satisfaction questionnaire to 643 veterans who had had agent orange examinations at seven VA medical facilities. Although 43 percent of the 356 veterans who responded said their examinations were not thorough, and 55 percent said that their examinations were only fair or poor, VA made no attempt to determine whether medical facilities were properly implementing the examination program or why veterans reported that they did not receive thorough examinations.

VA's Office of Environmental Medicine relies on the environmental physicians to insure that the agent orange program is properly implemented. However, the environmental physicians at the medical facilities we visited were not generally insuring that examinations were thoroughly conducted and documented. At eight of the facilities the environmental physicians did little or no review of the examination records. At the other six facilities the environmental physicians generally reviewed examination records to determine the physician's diagnosis and to insure that appropriate followup care was prescribed. However, none of the medical facilities we visited was evaluating the agent orange program as part of its systematic internal review program.

CONCLUSIONS

VA needs to monitor more closely the implementation of the agent orange program to insure that

- examinations are thorough and documented in veterans' medical records,
- examining physicians are familiar with available information on agent orange's potential health effects and efforts to develop more scientific information and that they provide this information to veterans, and
- medical facilities are providing examinations in a timely manner.

Furthermore, VA should revise the exposure history form and use the standard physical examination and medical history forms used for veterans admitted to VA facilities to elicit more detailed information from agent orange examinations and to simplify data collection for examining physicians.

RECOMMENDATIONS TO THE ADMINISTRATOR
OF VETERANS AFFAIRS

We recommend that the Administrator, through the chief medical director:

- Require VA medical facilities to include the agent orange examination program in the facilities' systematic internal review process.
- Revise the exposure history form and use the standard VA physical examination and medical history forms to gather more thorough information during agent orange examinations.
- Require environmental physicians to review all examination records to insure that examinations are thorough and documented.
- Direct VA physicians to document all findings for every factor described in VA agent orange program circulars for each examination.
- Reemphasize to VA medical facilities the importance of providing examinations in a timely manner.
- Direct VA medical facilities to insure that examining physicians are familiar with available information on agent orange and that they provide this information to all veterans examined.

AGENCY COMMENTS AND
OUR EVALUATION

In an October 1, 1982, letter, the Administrator of Veterans Affairs provided comments on a draft of this report. (See app. V.) While VA generally agreed with our recommendations, it offered a number of comments suggesting that the problems were not as serious as we maintained. As discussed below, we generally disagree with VA's assessment. The Administrator's comments are cause for concern as to whether VA accepts the need for concerted action to implement our recommendations.

Evaluation of VA's overall comments

VA agreed that problems existed in the agent orange examination program, but suggested that

- the examinations were more thorough than veterans perceived and examination records indicated,
- VA physicians used available information in conducting examinations, and

--the situation today is much different than it was when we did our fieldwork because of corrective actions taken.

Examinations were more thorough than reported

VA criticized the methodology we used to assess the adequacy of the physical examination because our conclusions were based on veterans' perceptions of their examinations and our review of examination records. According to VA, it is difficult for veterans to evaluate the performance of the examining physician because much of what is done during a physical examination is not apparent to the person being examined. VA provided several examples to suggest that examinations were more thorough than the veterans responding to our questionnaire perceived. VA said that our review of examination records determined the quality of the documentation not the thoroughness of the examination. According to VA, an evaluation of examination thoroughness probably cannot be accomplished by persons who are not qualified health care professionals.

Our report recognized that the examinations were more thorough than veterans perceived. (See pp. 6 to 8.) However, our review of examination records showed that problems existed, particularly when veterans had reported health problems as discussed on pages 8 and 12. Without concerted action to improve the thoroughness of examinations and change veterans' perceptions of the examination program, the program will not reduce veterans' concerns about agent orange.

VA's comments indicate an assumption that where documentation was missing, the physician elicited, but did not record the data. However, as shown on page 10, VA officials were unable to determine whether an individual question was not documented because there was no abnormal finding or because the information was not elicited.

Because examining physicians were not following program guidelines and eliciting adequate details on reported health problems we believe the examinations were poorly conducted not just poorly documented. As shown on pages 8 to 10, only 1 of the 14 VA medical facilities we visited elicited complete information on reported health problems. For the 1,175 past or present health problems identified in the records we reviewed, VA physicians documented (1) when the symptoms first appeared and the intensity of the symptoms only 55 percent of the time, (2) the degree of physical incapacitation only 32 percent of the time, and (3) the treatment that had been provided only 30 percent of the time. According to our medical advisor, not documenting such data indicates that the data may not have been elicited and that the examinations were not thorough.

Physicians used available information

VA said that our report implies that there is more knowledge about ill effects caused by herbicides than VA is providing veterans. According to VA, physicians find it difficult to offer any specific advice in response to veterans' inquiries about possible ill effects because chloracne is the only established relatively persistent effect of exposure to agent orange. Similarly, VA says that examining physicians would focus on specific body systems if there were more information available on the potential symptoms of exposure to agent orange.

As shown on pages 14 and 15, examining physicians at some VA facilities were not familiar with available information on agent orange and the potential symptoms of exposure. We recognize that conclusive evidence is not available about the potential adverse health effects of exposure to agent orange. However, we believe that VA physicians should be aware of, and provide to veterans, information about what is known and not known about agent orange. Not providing available information to veterans until conclusive evidence is available contributes to veterans' dissatisfaction with the examination program.

Although VA maintained that examining physicians cannot focus on specific body systems because of a lack of data on the potential symptoms of exposure to agent orange, VA program guidance has, since 1978, contained such data. However, as shown on page 15, some examining physicians were not familiar with the program guidance.

Problems identified have been corrected

VA said that we reached the conclusion that VA's efforts have been ineffective in addressing the concerns of Vietnam veterans by citing data from examinations given in 1979 and 1980 in conjunction with more current VA programs and initiatives. VA said that a more proper conclusion would have been that VA recognized many of the concerns identified and has taken appropriate corrective action.

VA offers little evidence to suggest that the deficiencies noted in examinations given in 1980 do not still exist. While we did not review records of examinations conducted after 1980, most of our review work was conducted in 1981 and 1982 to identify the underlying program deficiencies which contributed to the examinations' lack of thoroughness and to evaluate VA program initiatives which would have corrected the deficiencies. For example, although VA said in its comments that it issued the pamphlet "Worried About Agent Orange" in the summer of 1980 to insure that veterans were informed about agent orange, as discussed on page 41, only 24 of the 112 VA medical facilities we contacted a year later offered to send us the pamphlet. As shown below and elsewhere in this report,

VA has not taken effective action to eliminate the other program deficiencies, such as the poor design of examination forms and the lack of monitoring to insure examination thoroughness.

Include examination program in systematic internal review process

Although VA agreed with our recommendation, it said the review would be better accomplished as part of VA's systematic external review program rather than the systematic internal review process. According to VA, the systematic internal review program leaves to each medical center the selection of specific facility activities to review, whereas the systematic external review program reviews the quality assurance of each center's ambulatory care program. VA said that in the future the systematic external review program team member who surveys ambulatory care will review the agent orange program using detailed criteria now being developed.

We agree that the agent orange examination program should be included in the systematic external review program. However, because the teams visit each medical facility only every 2 or 3 years, reliance solely on the external review program for monitoring would mean that the thoroughness of examinations at some facilities would not be monitored for up to 3 years. By directing each VA medical facility to include the agent orange program in its annual systematic internal review program, VA could better insure that the agent orange program is closely monitored.

Direct environmental physicians to review all examination records

The Administrator said that our recommendation had already been implemented by a January 1981 circular which directed environmental physicians to advise veterans of their examination results. VA said this was further stressed in a February 11, 1981, Chief Medical Director's Information Letter that directed environmental physicians to inform veterans of the positive or negative findings of their examinations. VA said that the environmental physicians' prior review of each veteran's examination record is implied in these directives.

While the directives VA cited have resulted in veterans receiving their examination results they have not resulted in the environmental physician reviewing examination records. Although environmental physicians at the 14 medical facilities we visited told us that veterans were provided their examination and laboratory test results after the January 1981 directive, the results were generally provided by the examining physician, not the environmental physician. As discussed on page 16, most environmental physicians were not reviewing examination records to insure that the examinations were thorough and documented even after the two directives were issued.

Revise examination forms
and direct physicians to
document all findings

VA said that it is revising the agent orange examination reports and that it would be better to give specific direction concerning documentation at the time the new procedures are distributed. According to VA, a March 19, 1981, VA circular stipulated that standard VA physical examination forms be used to document the physical examination. VA said that the circular is currently being revised to include instructions on the use of the examination forms. VA said that the exposure history forms are also being revised and that it anticipated that the revised forms will be available to VA health care facilities in December 1982.

The circular cited in VA's comments--a reissuance of the original program guidance--does not stipulate that VA facilities use the standard admissions physical examination form. Rather, it gives the physician the choice of using either the standard admissions form or the shorter agent orange examination form. Only 5 of the 14 VA medical facilities we visited had used the standard admissions form and only one was using it routinely. VA, in revising the circular, should direct medical centers to discontinue use of the agent orange examination and medical history forms in favor of the standard admissions forms.

Reemphasize need to reduce
examination backlogs

VA said that for the past 2 years it has continually emphasized the need for prompt examinations and that the problem of excessive delays in providing agent orange examinations no longer exists. According to VA, for the last 17 months each facility has been reporting its monthly backlog and the number of agent orange examinations performed. VA said that from May through July 1982, only one facility (Anchorage) reported a backlog of 50 or more examinations. VA said that there is a regional office in Anchorage, but no hospital or clinic and that it is difficult to obtain contract physicians to perform the examinations. According to VA, other medical facilities have short waiting lists and almost always perform examinations within 30 days after they are requested.

As stated on page 15, VA has made progress in reducing examination backlogs. However, recent statistics on the backlog of examinations at VA medical facilities do not support VA's contention that VA medical facilities almost always perform examinations within 30 days. For example, although Anchorage was the only facility with a backlog of 50 or more examinations in each of the 3 months cited by VA, as of the end of July 1982, five medical facilities had backlogs of more than 50 examinations, and two of the five had more than 130 pending examinations. Further, based

on the number of examinations performed in July 1982, 79 (about 46 percent) of 172 VA medical facilities had more than a 1-month backlog of examinations at the end of the month.

VA needs to continue to emphasize to medical facilities the need to provide examinations in a timely manner.

Insure that examining physicians are familiar with available information

VA said that examining physicians will be kept informed of all agent orange information as it becomes available through national conferences, information mailings, and telephone conferences. VA did not agree, however, that this information should be provided to all veterans examined because it would serve no useful purpose. According to VA, examining physicians should discuss agent orange matters with the veterans as questions are raised, not as a routine to be followed as part of each examination.

While we would not expect examining physicians to provide each veteran all information on agent orange, physicians should ask veterans about their concerns about agent orange and provide them information relating to those concerns. At a minimum, each veteran should be provided VA's agent orange pamphlets and told where he or she can view VA's agent orange film.

CHAPTER 3

VA SHOULD DISCONTINUE THE AGENT ORANGE REGISTRY

VA's computerized agent orange registry does not contain specific diagnoses for the health problems found in Vietnam veterans or veterans' addresses. As a result, the registry is of little use in determining whether veterans are experiencing an unusual incidence of certain health problems, and it cannot be used to locate veterans for followup examinations. Although the registry's deficiencies could be corrected, the corrections would be costly and the data still could not be used as a basis for scientifically valid conclusions about veterans' health. Discontinuing the registry could save almost \$1 million a year in administrative staff and computer costs.

THE REGISTRY LACKS ADEQUATE INFORMATION ON HEALTH PROBLEMS EXPERIENCED BY VIETNAM VETERANS

Although VA established the computerized agent orange registry to determine what health problems were being experienced by Vietnam veterans exposed to agent orange, the registry does not contain specific diagnoses of health problems and lacks adequate exposure and medical history information to compare veterans' health problems with their degree of exposure to agent orange or the area of Vietnam where they served.

The registry contains general descriptions of the health problems identified by VA physicians during agent orange examinations, such as the number of veterans with skin diseases, neoplasia (tumors), or birth defects in their children, but it does not identify the specific types of skin conditions, tumors, or birth defects. For example, as of December 1981, the registry showed that 19 percent of the veterans examined had skin diseases, but it did not specify whether the skin problems were chloracne (a symptom of dioxin exposure), a common dermatitis, or a fungal infection, such as athlete's foot. Similarly, the registry showed that about 4 percent ^{1/} of the veterans examined had neoplasia (tumors), but it did not differentiate between malignant (cancerous) and benign (noncancerous) tumors; identify the location of the tumor; or indicate whether the tumor was a soft tissue sarcoma like those found in humans exposed to phenoxy herbicides, such as agent orange. While the registry indicated that almost 8 percent of the veterans examined reported having children with birth defects, it does not identify the type of defects reported, such as cleft palate or

^{1/}As noted on page 25, VA later found that only about 1 percent of the veterans examined had neoplasia.

renal abnormalities. As a result, the registry cannot be used to determine whether Vietnam veterans are experiencing an unusual incidence of chloracne or other skin conditions, what types of tumors they have and in what locations, or what types of birth defects their children have.

In addition to insufficient descriptions of veterans' health problems, the registry lacks data on the sex of the veterans examined. As a result, VA cannot determine whether (1) the 49 veterans with gynecological diseases represent a significant proportion of the females examined and (2) children of female Vietnam veterans have experienced an unusual incidence of birth defects.

Furthermore, the registry does not contain adequate exposure and medical history data and physical examination findings to permit comparisons of veterans' health problems with their degree of exposure or the area of Vietnam where they served because such information is not elicited in the agent orange examination. As discussed on pages 11 and 12, this problem is primarily because of the poor design of the examination forms.

LACK OF ADDRESS INFORMATION PREVENTS USE OF REGISTRY FOR FOLLOWUP

Although the agent orange registry was intended to facilitate followup with veterans who had agent orange examinations, VA had not included veterans' addresses in the agent orange registry, and the locator cards at half the facilities we visited did not contain adequate information for followup contact with veterans. A 1974 World Health Organization report entitled "Current and Future Uses of Registers in Health Information Systems" states that one essential use of a registry is to identify and locate individuals. Although VA's Data Analysis Task Force identified this weakness in 1980, no action has been taken to resolve the problem.

Since 1978, VA medical facilities have been required to maintain a locator card file with the name, complete address (including zip code), and social security number of each veteran who had an agent orange examination. The locator system was intended to facilitate any future followup with veterans. However, only 8 of the 14 medical facilities visited maintained adequate information in the locator card system to permit followup contact with veterans, and none of the facilities routinely updated the locator card files. Based on our review of a random sample of locator cards at each facility, we found that complete addresses were lacking for

--75 percent of the cards reviewed at the Chicago-Westside
medical center,

--98 percent of the cards reviewed at the Los Angeles-Wadsworth medical center, and

--98 percent of the cards reviewed at the East Orange medical center.

Generally, the cards were missing the veterans' city, State, and zip code. We also identified at least one veteran in the locator card files at each facility who, according to their medical records, had not completed or never had examinations.

To send our questionnaire to a random sample of about 1,100 veterans who had received agent orange examinations, we asked each medical facility to provide the addresses of veterans in our sample who had their examination at that facility. About 9 percent of the questionnaires we sent out were undeliverable.

REGISTRY CONTAINS INACCURATE
AND UNRELIABLE DATA

Extensive coding errors and duplicate records have been identified in the registry by VA's Inspector General and program officials. Although the coding sheets are difficult to complete, only 3 of the 14 facilities we visited were reviewing the coding sheets to insure their accuracy, and central office officials had taken few actions to improve the reliability of registry data.

A July 1981 report by VA's Inspector General found that 43 percent of the records entered into the registry during the processing cycle at the end of 1980 contained coding errors. Furthermore, Inspector General staff told us that the registry contained more than one agent orange examination for some veterans because the system could not detect duplicate records. The Inspector General found that examinations entered in the registry, which were later found to be inaccurate and returned to the medical facility for revision, could be reentered into the registry without deleting the previously inaccurate record. The Inspector General's report concluded that, because of the lack of internal controls to prevent duplicate records from entering the system, the number of examinations was overstated, and incorrect statistics were generated which compromised the value and integrity of the registry.

Our review of about 4,000 examinations included in the registry as of October 1980 identified 118 (3 percent) duplicate records. In addition, we identified six veterans entered in the registry who had not completed an examination.

VA central office officials reviewed the examination records of veterans shown in the registry as having tumors because of the unusually high number of tumors diagnosed. They found that three out of every four entries for tumors in the registry were wrong due to coding errors. Nonetheless, as of June 1982, VA central

office had not corrected the inaccurate tumor data or assessed the reliability of other data in the registry.

The administrative staff at five of the VA medical facilities we visited said that the coding sheets were difficult to complete and may have resulted in coding errors. The staff at one facility said that they had to interpret the physicians' comments because the medical history and physical examination sections of the data collection forms require physicians to provide handwritten descriptions of their findings.

In addition, administrative staff at four facilities said that the coding instructions prepared by VA's central office contribute to inconsistent coding because they permit discretion in coding certain kinds of information. For example, VA staff preparing the coding sheets were instructed to use their "best judgment" in coding the number of exposures and types of contact with agent orange because the questions from the data collection form were general and may result in veterans' providing unspecific responses. VA staff were also instructed to record "unsure" answers regarding the veterans' contact with agent orange as "no the veteran did not experience any of the listed types of contact," although the coding sheet permitted entering uncertain responses. Coding instructions also directed VA staff to record "unknown" answers as "no" answers to such other questions as "Did veteran wear protective gear?"

Although VA medical facilities were instructed in January 1980 to review all coding sheets to insure their completeness and accuracy, only 3 of the 14 medical facilities we visited were reviewing coding sheets. A fourth facility reviewed the coding sheets to see if all the boxes were filled in, but did not review the accuracy of the entries. In March 1981, officials at the Long Beach medical center told us that they had not submitted any coding sheets because they lacked adequate administrative staff to complete them. Subsequently, in April 1981 Long Beach officials initiated action to submit backlogged coding sheets.

VA HAS MADE LITTLE USE OF THE REGISTRY

Although VA prepares monthly reports summarizing the data in the registry, the special assistant to the chief medical director for environmental medicine told us that little use has been made of the information because it contains many flaws and is drawn from a self-selected population which cannot be used as a basis for scientific conclusions about the health problems being experienced by veterans.

In October 1980, the Chairman of VA's Data Analysis Task Force responsible for analyzing the information in the agent orange registry told VA's Agent Orange Policy Coordinating Committee that the information in the registry was not suitable for making scientific

conclusions about the health status of Vietnam veterans because the registry data were drawn from a self-selected population. The Task Force recommended that the collection of health data be discontinued and that the registry include only the veteran's name, address, telephone number, and social security number. However, the Committee decided to continue collecting health data for the registry to maintain general information on the health of veterans examined.

While VA is reluctant to release the registry data because it may be construed as an epidemiology study, VA officials believe the registry data would be helpful in planning the epidemiology study mandated by Public Law 96-151 and in conducting followup examinations to determine whether the health status of previously examined veterans had changed. However, as shown on pages 23 and 24, the registry's lack of specific information on veterans' health problems makes it of limited use to researchers planning the epidemiology study. The draft protocol for the epidemiology study relied on the findings of past scientific studies to determine what symptoms should be looked for in veterans. Furthermore, according to a central office agent orange official, VA has no plans to conduct followup examinations with previously examined veterans to see if their health has changed because there is no medical need for the examinations, they would be costly, and the findings would have no scientific value.

REVISING THE REGISTRY COULD BE COSTLY

VA estimates indicate that almost \$2.7 million has been spent on the agent orange registry from its inception in January 1980 through August 1982. The registry, however, contains a number of deficiencies. Revising the registry to improve its usefulness would require additional programming and staff which VA officials acknowledge would be costly.

VA estimated that about \$85,000 was spent to start up the registry, including the purchase of equipment and planning, programming, and testing the system. The monthly recurring cost of entering data from agent orange examinations and programming is estimated to be about \$8,500. The largest portion of the registry's cost is for completion of coding sheets at VA medical facilities. According to VA, about \$892,000 is spent annually for the time taken by administrative staff to complete the coding sheets at VA medical facilities.

Several actions would be necessary to correct the registry's deficiencies. First, the addresses of over 89,000 veterans who have had examinations would have to be determined and entered into the registry's computerized data base. Second, VA medical facilities would have to develop procedures for updating veterans' addresses. Third, the data entered into the registry for each veteran would have to be checked against the veteran's examination

record to correct the inaccurate data and delete duplicate records. Finally, VA medical facilities would need to increase administrative staff time to review the coding sheets to insure their accuracy.

Although we did not estimate the cost of revising the registry, the additional computer programming and staff time necessary to make the revisions suggests that it would be significant. Discontinuing the completion of coding sheets at VA medical facilities and entry of data into the computer could save almost \$1 million a year.

CONCLUSIONS

VA's computerized agent orange registry is of little use in determining what health problems are being experienced by Vietnam veterans exposed to agent orange and in locating veterans for followup examinations. Limiting the registry to the veteran's name, address, telephone number, and social security number could save almost \$1 million a year in administrative expenses.

RECOMMENDATIONS TO THE ADMINISTRATOR OF VETERANS AFFAIRS

We recommend that the Administrator, through the chief medical director, discontinue the computerized agent orange registry and maintain a list of veterans who have had agent orange examinations.

AGENCY COMMENTS AND OUR EVALUATION

VA disagreed with our recommendation to discontinue the computerized agent orange registry. In our view, the reasons VA cited for maintaining the registry are not consistent with other comments it provided.

According to VA, the registry is needed because it is the most extensive list of veterans who have had agent orange examinations. Yet, elsewhere in its comments, VA acknowledged that it had established a separate automated mailing list of the same veterans. Also, VA maintained that the registry is an important mechanism for detecting significant health trends in the Vietnam veteran population which may differ from the general population. However, in commenting on another recommendation, VA stated that

"such statistics cannot be used to compare the prevalence of illnesses or disabilities reported by Vietnam veterans with that of the general population because the veterans examined are a self-selected population * * *."

Finally, VA said that the registry enables VA to determine areas requiring more indepth medical or scientific analysis, but disagreed with our recommendation that it do such analyses of skin problems, tumors, and birth defects identified in agent orange examinations.

VA could save almost \$1 million a year by discontinuing the computerized agent orange registry and continuing the automated mailing list.

CHAPTER 4

VA SHOULD DO MORE TO

ALLEVIATE VETERANS' CONCERNS

Most veterans responding to our questionnaire sought agent orange examinations because they were concerned that they, or their children, may have health problems, such as chloracne, cancer, and birth defects which may have been caused by exposure to agent orange. While most veterans seeking agent orange examinations had health problems, data from the examinations suggest that the health problems may have been caused by factors other than agent orange. Dermatologists at VA medical facilities have generally seen only common skin problems in veterans, and the Armed Forces Institute of Pathology found few unusual tumors or growths in tissue samples taken from Vietnam veterans.

Although many veterans' dissatisfaction with what VA did for them appears to have resulted, in part, from a lack of understanding of the examination's limitations, VA has not effectively used the data gathered from agent orange examinations to identify unusual health problems or alleviate veterans' concerns by determining whether the veterans' health problems were caused by something other than service in Vietnam. Specifically, VA has not

- adequately informed veterans about what to expect from the examination,
- compiled statistics on the health problems of primary concern to veterans,
- insured that medical facilities were identifying and submitting tissue samples to the Armed Forces Institute of Pathology,
- provided veterans available information about agent orange's potential for causing birth defects in children, and
- provided examination results to many veterans examined before January 1981.

We believe VA could alleviate the concerns of some veterans by providing them more information on the health problems about which they are primarily concerned.

AGENT ORANGE EXAMINATIONS ARE NOT ALLEVIATING VETERANS' CONCERNS

Veterans responding to our questionnaire went to VA for an agent orange examination because they were concerned that they had

health problems caused by agent orange exposure and that exposure to agent orange could affect their health as well as their children's health. Many veterans, however, were dissatisfied with what VA did to alleviate their concerns. For example, of the

- 87 percent who wanted to be examined to see if they had any health problems caused by agent orange, 63 percent were dissatisfied with the examination VA provided;
- 80 percent who wanted to find out what could happen to their health if exposed, 73 percent were dissatisfied with the information VA provided about the health effects of exposure;
- 74 percent who wanted to be examined or tested to see if they had been exposed, 60 percent were dissatisfied with what VA told them about their exposure;
- 73 percent who wanted to know if agent orange could affect their children's health, 74 percent were dissatisfied with what VA told them about birth defects;
- 71 percent who wanted to be examined for health problems they had which they believed were caused by agent orange, 68 percent were dissatisfied with VA's examination of these problems; and
- 60 percent who wanted to find out if they served in a place in Vietnam where they could have been exposed, 67 percent were dissatisfied with what VA told them about their exposure.

VA NEEDS TO BETTER INFORM VETERANS OF EXAMINATION LIMITATIONS

Although veterans' dissatisfaction with what VA did for them appears to have resulted, in part, from a lack of understanding of the examination's limitations, VA was not providing veterans adequate information about what they could expect from the examination.

While most veterans went to VA because they were concerned about health problems, about 74 percent of the veterans responding to our questionnaire cited the desire to be examined to determine whether they had been exposed to agent orange as a reason for seeking an examination. However, routine tests to detect the presence of dioxin in the body have not been perfected. Also, VA does not maintain information on where troops served in Vietnam; such information would be necessary to respond to the concerns of the 60 percent of our questionnaire respondents who wanted VA to tell them if they had served in an area where they could have been exposed.

VA LACKS STATISTICS ON THE TYPES OF
SKIN PROBLEMS IDENTIFIED IN VETERANS

Although skin conditions were a primary concern of veterans seeking agent orange examinations, VA has not compiled statistics on the types of skin problems identified in veterans. As a result, VA has no summary data to indicate whether veterans are experiencing chloracne induced by agent orange exposure or common skin problems caused by something other than agent orange.

About 54 percent of the veterans responding to our questionnaire sought agent orange examinations because they had skin problems, and VA told about 26 percent that they had skin problems. Dermatologists at the 14 medical facilities we visited and the Chairman of VA's Chloracne Task Force told us in April 1982 that they had not seen any cases of chloracne in Vietnam veterans, but they had seen common skin conditions, such as dermatitis or fungal infections. Thirteen of the 267 skin samples analyzed by the Armed Forces Institute of Pathology as of December 1981 were malignant tumors, all of which were common with no unusual features. No cases of chloracne were identified in the samples submitted, and the largest single group of skin samples was diagnosed as chronic dermatitis.

However, VA's agent orange registry does not specify the types of skin problems being identified in veterans. As a result, VA cannot determine how many veterans had chloracne, a symptom of agent orange exposure, or a common dermatitis or fungal infection which could be caused by some other factor in Vietnam or by something other than service in Vietnam. By compiling these statistics from examination records and providing them to veterans, VA could show veterans seeking agent orange examinations that the skin conditions being found in veterans are for the most part common conditions found in the general population, rather than chloracne.

VA HAS NOT RELEASED TISSUE
SAMPLE ANALYSIS OR INSURED
THAT SAMPLES ARE SUBMITTED

Although cancer is a major concern of Vietnam veterans, as of August 1982, VA had not reported the findings of the tissue sample analysis performed by the Armed Forces Institute of Pathology or insured that VA medical facilities submitted tissue samples of tumors or growths taken from Vietnam veterans to the Institute.

VA established a special registry at the Armed Forces Institute of Pathology in September 1978. The registry was intended to evaluate tissue samples from Vietnam veterans and identify any unique pathologies to determine whether (1) any unusual or unique tumors are occurring in any organ or organ system, (2) veterans

serving in a particular military unit in Vietnam have an unusually high incidence of tumors, or (3) tumors are occurring at an unusually early age. VA medical facilities were directed to submit all tissue samples taken from Vietnam veterans to the registry.

In a January 1982 report, the Armed Forces Institute of Pathology noted that 62 of 604 registry samples analyzed were malignant tumors; however, only 6 had unusual features. The malignancies were most frequently located in the lungs (14 cases), skin (13 cases), lymph nodes (9 cases), and gastrointestinal tract (8 cases). Based on the analysis of the first 604 tissue samples the report concluded that no findings appeared worthy of further analysis.

Although the Armed Forces Institute of Pathology had received 519 of the 604 tissue samples from VA medical facilities, only 79 of the 172 facilities had submitted samples by the end of 1981. One reason that more facilities did not submit samples is that they were unaware of the requirement to send tissue samples to the Institute or they did not determine which tissue samples came from Vietnam veterans. As of April 1981, pathologists at 9 of the 14 facilities we visited were either unaware of or misinterpreted VA's requirements to send tissue samples of tumors or growths taken from Vietnam veterans to the Institute or had no procedures to identify which tissue samples were taken from Vietnam veterans. However, one of the nine facilities had submitted tissue samples by the end of 1981. As a result, VA's program to detect unusual or unique tumors in tissue samples taken from Vietnam veterans may not include all veterans diagnosed as having these health problems.

VETERANS WERE NOT PROVIDED ADEQUATE INFORMATION ON BIRTH DEFECTS

Although birth defects were a major concern of veterans seeking agent orange examinations, VA medical facilities were not providing them available information on birth defects or referring them to genetic counseling services for such information. Nor had VA analyzed the veterans' examination results to determine whether the veterans' children were experiencing an unusual type or incidence of birth defects.

About 74 percent of the veterans responding to our questionnaire cited concern about birth defects as one reason they sought an agent orange examination; 17 percent said that they had a child with birth defects. However, only about 10 percent of the veterans responding to our questionnaire said that VA had given them information on what could happen to their children's health if they were exposed to agent orange. Three out of four veterans who went to VA to find out whether agent orange could affect the health of their children were dissatisfied with what VA told them.

VA's agent orange pamphlets address birth defects, but provide only a brief explanation of available scientific data. Both the pamphlet "Worried About Agent Orange" issued in July 1980 and the June 1982 replacement "Agent Orange: Information for Veterans Who Served in Vietnam" state that there is no medical evidence to establish that exposure to agent orange has caused birth defects in the children of Vietnam veterans. The June 1982 pamphlet briefly identifies studies showing that (1) industrial workers exposed to the ingredients of agent orange have not fathered an increased proportion of children with birth defects and (2) male mice treated with agent orange experienced no effect on fertility or on the rate of birth defects.

The pamphlet, however, does not discuss other studies, including those which led to the original concern about birth defects, or note that VA's literature review of herbicides concluded that adequate studies of agent orange's potential for causing birth defects had not been performed. Furthermore, the pamphlets do not provide data on the types and incidence of birth defects in the general population. According to the Director of VA's Agent Orange Research and Education Office, VA will develop a monograph to provide such information.

During an October 20, 1980, conference call with VA medical centers, an official at the Wood medical center suggested that veterans who report a reproductive history of birth defects during agent orange examinations be provided genetic counseling on a fee basis. VA's Office of Environmental Medicine strongly supported the use of fee basis genetic counseling at that time and suggested that an agency policy be developed. Subsequently, in November 1981, VA sent each medical facility a genetic counseling services directory prepared by the March of Dimes Birth Defects Foundation. As of August 1982, only 2 of the 14 medical facilities we visited told us they had referred a total of three veterans to genetic counseling services. However, VA had not authorized payment for these services.

According to VA's computerized agent orange registry, about 8 percent of the veterans who have had agent orange examinations have children with birth defects. However, VA has not identified the kinds of birth defects experienced by these children. As a result, VA did not know whether children of Vietnam veterans were experiencing an unusual type of or incidence of birth defects in relation to birth defects in the general population.

MANY VETERANS EXAMINED BEFORE 1981
HAVE NOT RECEIVED THEIR RESULTS

Before January 1981, VA did not require medical facilities to provide veterans the results of their agent orange examination and laboratory tests. As a result, many veterans did not receive their

examination results. Although VA compiled a list of addresses for all veterans who received an agent orange examination, VA does not plan to contact veterans and tell them how they can obtain their examination results if they have not already received them.

About 66 percent of the veterans responding to our questionnaire had not been provided the results of their laboratory tests, and 31 percent said VA told them nothing about their examination results. In October 1980, a VA patient satisfaction survey sent to veterans who had agent orange examinations found that about 56 percent of the respondents had not been given the results of their physical examination by a VA physician, and about 80 percent had not been told the results of their laboratory tests. As a result, a January 1981 VA circular required medical facilities to provide veterans their physical examination results, and send veterans followup letters explaining all examination and laboratory test results. Environmental physicians at the facilities we visited told us that veterans were now receiving their examination results.

CONCLUSIONS

Alleviating the concerns of Vietnam veterans about their health is an important function of the agent orange examination program until more specific information on the herbicide's long-term health effects is developed. VA should tell veterans (1) about the examination's limitations, (2) the results of their examinations and laboratory tests, and (3) the types and potential causes of health problems experienced by veterans who have had agent orange examinations.

RECOMMENDATIONS TO THE ADMINISTRATOR OF VETERANS AFFAIRS

We recommend that the Administrator, through the chief medical director:

- Direct VA medical facilities to inform veterans seeking agent orange examinations of the examination's limitations.
- Develop and analyze statistics on the kinds of skin problems, tumors, and birth defects identified in agent orange examinations, and make this information available to veterans.
- Emphasize to VA medical facilities the importance of sending tissue samples taken from veterans who served in Vietnam to the Armed Forces Institute of Pathology.
- Develop a monograph on agent orange's potential for causing birth defects.

--Direct VA medical facilities to provide available information to veterans concerned about birth defects or to refer veterans to genetic counseling services for such information.

--Direct VA medical facilities to follow up with all veterans examined before January 1981 to insure that they have been provided their examination results.

AGENCY COMMENTS AND
OUR EVALUATION

VA agreed with our recommendations that it (1) inform veterans of the agent orange examination's limitations, (2) emphasize to VA medical facilities the importance of sending tissue samples to the Armed Forces Institute of Pathology, (3) develop a monograph on birth defects, and (4) provide veterans available information on birth defects. According to VA, action was taken to implement some of our recommendations during an August 13, 1982, nationwide conference call held after it was provided a draft of this report. However, VA did not agree that veterans should be provided data on the types of health problems identified in agent orange examinations or that veterans examined before January 1981 should be provided their examination results.

Inform veterans of
examination's limitations

VA agreed with our recommendation and said that several actions have been or will be taken to inform veterans of the agent orange examination's limitations. According to VA, among other activities, it prepared and widely distributed the pamphlet "Agent Orange Information for Veterans Who Served in Vietnam--Questions and Answers" which specifically addresses the examination's limitations. VA also said that environmental physicians were instructed during educational conferences in 1979 and 1980 to explain the purpose of the examination process to veterans receiving examinations. VA said that it had also informed the media and administrative staff of veterans' organizations of the intent, nature, and limitations of the examination.

VA, in an August 13, 1982, conference call to its medical centers instructed health care staff to define the limitations of the agent orange examinations. According to VA, these instructions will be outlined in a soon to be published Chief Medical Director's letter.

Analyze and release data
on types of health problems

VA said it disagreed with our recommendation to analyze and release data on the kinds of skin problems, tumors, and birth defects identified in agent orange examinations because the intent of

our recommendation was not clear and might serve to unduly alarm veterans without providing useful information. According to VA, information gained by the development and analysis of such statistics cannot be used to compare the prevalence of illnesses or disabilities reported by Vietnam veterans with that of the general population because the veterans examined are a self-selected population and more prone to report real or perceived illnesses or disabilities. VA said that, as a result, any statistical report on prevalence that is based on registry data implies a much greater prevalence among all Vietnam veterans than is actually the case.

Our recommendation was intended to accomplish one of the initial objectives of VA's examination program, that of providing information on the specific health problems being experienced by veterans concerned about the adverse health effects of agent orange.

We agree with VA that data from the agent orange examinations cannot be used to compare the prevalence of illnesses or disabilities reported by Vietnam veterans with that of the general population. However, if, as the information on skin problems and tumors on pages 32 and 33 suggests and VA maintains in the current agent orange pamphlet, there are no characteristic symptoms or diseases among a population which sought agent orange examinations because they were experiencing health problems, such data would alleviate, not create, undue concerns.

Send tissue samples
to special registry

VA said that it has emphasized and will continue to emphasize the importance of the special registry at the Armed Forces Institute of Pathology. According to VA, past activities relating to the tissue registry have included

- issuing a series of four circulars directing VA medical centers to send tissue samples to the Institute;
- discussing the tissue registry during March 16, 1981, and March 27, 1982, conference calls with environmental physicians, chiefs of staff, and other key staff at all VA medical centers;
- discussing the tissue registry in the July 1981 issue of the Agent Orange Bulletin; and
- sending transcripts of the VA Advisory Committee on Health Related Effects of Herbicides to all environmental physicians.

According to VA, the earlier poor cooperation in submitting tissue samples was due in large part to the lack of an indicator for in-country Vietnam service in VA medical records. VA said that this deficiency was corrected by a July 14, 1982, Department of Medicine and Surgery circular.

Also, VA said that the need to send tissue samples to the special registry was addressed during an August 13, 1982, nationwide conference call with VA field staff. VA said that a Chief Medical Director's letter reemphasizing the need to provide tissue samples to the Armed Forces Institute of Pathology will be released shortly.

Although VA cited several past activities relating to the tissue registry, the activities cited, with the exception of the conference call made after VA received a draft of this report, generally did not emphasize the importance of sending tissue samples to the Armed Forces Institute of Pathology. For example, VA said it issued a series of four circulars directing VA medical facilities to send tissue samples to the Institute. Review of the circulars revealed, however, that the first circular established the initial requirement that tissue samples be sent to the Institute, and the other three circulars in the "series" were annual reissues of the original circular.

VA also cited a July 14, 1982, circular establishing an in-country Vietnam service indicator as correcting the problem of identifying which tissue samples came from Vietnam veterans. However, the circular applies only to patients admitted to VA hospitals, nursing homes, and domiciliaries, not to the outpatient agent orange examination program. Further, the data gathered are not provided to VA pathologists--the officials responsible for sending tissue samples to the Institute. VA should direct physicians sending tissue samples from Vietnam veterans to pathology to identify the sample as coming from a Vietnam veteran. Such information has been available in the agent orange examination record since the program began in 1978.

Develop birth defects monograph

VA said that the Administrator approved funds for a monograph series on June 30, 1982, and that one of the series--"Birth Defects/General Screening" was funded for fiscal year 1982. According to VA, it is now seeking a consultant who will prepare the monograph, which has a December 1983 completion date.

Provide veterans available
information about birth defects

According to VA, our recommendation has been implemented. VA said that on September 18, 1981, it forwarded a copy of the March of Dimes Birth Defect Foundation publication "Birth Defects/Genetic Services," to all environmental physicians. The publication is an international directory of genetic counseling services. VA said that physicians had been instructed to refer veterans to one of these facilities when they request special genetic testing and counseling.

We do not believe VA's actions are adequate. Although VA transmitted the directory to its environmental physicians, the transmittal memorandum did not instruct the environmental physicians to refer veterans to a genetic counseling service. Rather, the directory was transmitted "for your information." As shown on page 34, as of August 1982 only 2 of the 14 medical facilities we visited had referred veterans to genetic counseling services.

Subsequent to receipt of a draft of this report, VA, in an August 13, 1982, conference call with VA medical centers, reminded them that they had been sent the directory and told them that it " * * * can be used to refer Vietnam veterans for these services when they are anxious to get specialized advice." However, VA has not directed its medical centers to provide veterans available information about birth defects or refer them to genetic counseling services.

Provide examination results to veterans
examined before January 1981

VA did not agree that veterans should be provided the results of examinations performed before January 1981 because of their greatly diminished usefulness. According to VA, receiving belated results 1 or 2 years after examination could, in fact, unduly alarm veterans. VA said that the results of agent orange examinations are permanently maintained in the veterans' medical records and are available to veterans upon request.

We do not agree that providing veterans the results of examinations conducted before January 1981 would unduly alarm veterans. At a minimum, VA should send a letter to veterans examined before January 1981 notifying them that some veterans may not have received their examination results and that the results are available upon request.

CHAPTER 5

VA NEEDS TO IMPROVE EFFORTS

TO ADVISE VETERANS OF THE AVAILABILITY OF AGENT ORANGE INFORMATION AND SERVICES

Although VA studies have concluded that disseminating information on agent orange and VA services is the most important factor in alleviating veterans' concerns about the potential health effects of agent orange, VA has not widely distributed informational material or publicized the availability of such information and the agent orange examination. About 80 percent of the veterans responding to our questionnaire were dissatisfied with the amount of information VA provided them, and 55 percent received no information from VA. The success of outreach efforts conducted by three States and one VA medical center indicates that many veterans are not aware of the availability of VA's agent orange services.

VA STUDIES IDENTIFY NEED FOR DISSEMINATION OF AGENT ORANGE INFORMATION

Two studies completed in early 1980 by VA's Office of Planning and Program Evaluation concluded that the primary need of most Vietnam veterans concerned about agent orange is for additional information about agent orange and available VA services. The studies recommended that VA extensively disseminate accurate information about agent orange to veterans and the media.

The first study analyzed agent orange-related inquiries received by VA regional offices to measure the level of public concern about the health effects associated with agent orange exposure. Although the number of inquiries was small, the study found that most of the inquiries (97 percent) were requests for information about medical problems, general information about agent orange, and VA compensation. The study concluded that the predominance of this type of inquiry demonstrates Vietnam veterans' concern about agent orange and their need for information.

In the second study, VA reviewed 148 newspaper articles to determine the effect of media coverage on veterans' concerns about agent orange. The study concluded that veterans' concerns may have been motivated by inaccurate and incomplete newspaper articles.

INFORMATIONAL MATERIALS
NOT WIDELY DISTRIBUTED

Although VA has prepared informational materials on agent orange, veterans can generally obtain these materials only at a VA medical facility, regional office, or outreach center. However, VA medical facilities we contacted by telephone did not generally offer to send us VA's agent orange pamphlet or tell us about VA's agent orange film. Fifty-five percent of the veterans responding to our questionnaire said that VA did not provide them any information on agent orange.

Agent orange pamphlet

In July 1980, VA issued an informational pamphlet--"Worried About Agent Orange?"--describing agent orange, its uses in Vietnam, concerns about its health effects, and the findings of scientific studies. The pamphlet tells veterans concerned about medical problems that may be agent orange related to contact the nearest VA medical facility for an examination or additional information.

Although about 500,000 pamphlets were distributed to VA medical facilities, regional offices, and outreach centers, the pamphlets were made available primarily to veterans visiting the facilities. Only about 8,300 pamphlets (less than 2 percent) were distributed outside the VA system to veterans' service organizations, and State and community groups.

At 10 of the 14 medical facilities we visited pamphlets were available in waiting or examining areas. However, only 4 of the 10 facilities directed VA staff to provide the pamphlets to veterans calling the facility or presenting themselves for an examination. Only 24 of the 112 VA medical facilities we contacted in our telephone survey (about 21 percent) told us that the pamphlet was available at the facility or offered to send us a pamphlet.

In April and June 1982, VA issued two revised agent orange pamphlets. According to an official in VA's Office of Public and Consumer Affairs, the pamphlets were mailed to all veterans in the registry.

Agent orange film

In February 1981, VA distributed the film "Agent Orange: A Search for Answers" to all VA medical facilities, outreach centers, and regional offices. The film describes what is currently known about the human health effects of agent orange exposure, how veterans may have come in contact with agent orange, what areas of Vietnam were heavily sprayed, and how veterans can participate in VA agent orange activities.

Although VA facilities were told to make the film available to local veterans' organizations, civic leaders, and the media, in addition to showing the film to VA staff and patients waiting in the outpatient clinics, only 3 of the 14 medical facilities we visited had shown the film outside the facility as of October 1981. These included showings on television stations and showings to veterans' organizations, the Red Cross, the staff at non-VA medical facilities, and the personnel in university medical departments.

Although all VA facilities were showing the film in outpatient waiting rooms, only 2 of the 112 VA medical facilities we contacted to inquire about agent orange told us about the availability of the film. Since eligibility for outpatient care is limited, it is unlikely that most veterans will have the opportunity to see the film unless VA more widely publicizes its availability.

OUTREACH PROGRAMS HAVE IDENTIFIED VETERANS WHO WANT INFORMATION

Three States and one VA medical center have conducted outreach efforts which have identified veterans who wanted information about agent orange or an examination. About 19 percent of all examinations conducted as of May 31, 1982, had been performed at VA medical facilities in the three States with outreach programs (Minnesota, New Jersey, and Wisconsin) or at facilities in neighboring States which served veterans from the three States. The success of these outreach programs indicates that many veterans were not previously aware of the agent orange services available through VA.

In 1979, Minnesota conducted an outreach program to notify veterans of their eligibility for the VA agent orange examination. County veterans' service officers contacted Vietnam veterans through discussions at veterans' meetings, door-to-door and telephone campaigns, and notices in local newspapers. Veterans were asked to complete a questionnaire which asked them if they wanted a free medical screening from VA.

According to the Minnesota Department of Veterans Affairs, the outreach efforts identified about 6,000 veterans who wanted to participate in VA's agent orange examination program. Before the start of Minnesota's program in 1979 only about 70 veterans had received agent orange examinations at the Minneapolis VA medical center. However, by November 30, 1981, the number of veterans examined at the facility was about 5,500.

In February 1980, New Jersey became the first State to establish a commission to assist veterans concerned about agent orange. By February 1982, the commission had mailed a self-help guide containing questions and answers about agent orange and information about VA's agent orange examinations and other services to

about 60,000 veterans. The commission staggered the mailing of its guide to veterans to control the demand for examinations and limit the burden on VA medical facilities.

The commission's outreach efforts appear to have increased demand for agent orange examinations. For example, according to the commission, the Philadelphia VA medical center, which serves New Jersey veterans, had examined only 144 veterans before February 1980. As of May 31, 1982, about 2,200 had been examined. In addition, the commission worked with VA medical facilities which serve New Jersey veterans to insure that veterans were provided timely and thorough examinations. For example, the commission arranged for Saturday examinations at the Philadelphia, East Orange, and Lyons VA medical centers.

In mid-1981, the Wood, Wisconsin, VA medical center and a Milwaukee television station produced a brief public service announcement encouraging veterans with medical problems which might be agent orange related to contact VA for an examination. The station paid all costs for the announcement and showed it about three times a day beginning in October 1981.

The environmental physician at the Wood VA medical center told us that the announcement has increased the number of veterans requesting examinations and improved the medical center's relations with Vietnam veterans' groups. He said that, although the demand for examinations increased, backlogs have remained low, and there has been no significant strain on the facility's staff or resources. According to the environmental physician, almost all veterans seeking examinations say they came in because they saw the announcement.

Another factor that may have increased demand for agent orange examinations in Wisconsin is the State's outreach effort. The State established an agent orange hotline in August 1980 as part of its Agent Orange Identification and Assistance Program. According to the program's coordinator, about 5,000 calls had been made to the hotline as of April 1982. Callers were instructed to contact their local county veteran service office if interested in filing a claim or obtaining a VA examination. In addition to the hotline, the State distributed a questionnaire to determine the effects of agent orange and Vietnam service on veterans. According to outreach program officials, more than half of the about 29,000 veterans who responded asked for additional information about agent orange, and 96 percent said they had not had a VA agent orange examination.

CONCLUSIONS

Agent orange informational materials prepared by VA were not reaching many veterans because VA had not effectively advised veterans of their availability. Public service announcements and State and private outreach programs have been much more successful

in assisting and encouraging veterans to obtain information and an examination from VA.

RECOMMENDATIONS TO THE ADMINISTRATOR
OF VETERANS AFFAIRS

We recommend that the Administrator, through the chief medical director:

- Direct all VA medical facilities to offer to send the agent orange pamphlet to all telephone callers interested in information about agent orange and advise callers when and where they can see the agent orange film.
- Use public service announcements to advise veterans of VA agent orange services.
- Work with State veterans' affairs offices to advise veterans of available VA agent orange services.

AGENCY COMMENTS AND OUR EVALUATION

VA agreed with our recommendations and said that several actions have been or will be taken to strengthen its outreach efforts.

Distribute agent orange
pamphlet and film

VA said that our recommendation is being implemented. According to VA, medical centers were advised during August and September 1982 conference calls to use the agent orange pamphlets and film. VA said that the conference calls will be followed by a chief medical director's letter reminding them of the recommended actions.

VA pointed out that the pamphlet "Worried About Agent Orange?" is now out of date and out of print. VA said that three new pamphlets were distributed early this year and cover a broad spectrum of information. According to VA, more pamphlets will be published and made available to VA facilities.

Use public service announcements
to publicize agent orange services

VA said that it is using public service announcements to provide an information and education program for concerned Vietnam veterans and their families. According to VA, an automated mailing list was developed for the agent orange registry and in June 1982, over 80,000 letters were mailed to veterans on the registry, along with two newly published information pamphlets. VA said that the mailings will continue as additional publications are issued.

VA said that other outreach efforts will include, but not be limited to, a display and franked card return mailers at all VA facilities, print and broadcast public service announcements directing interested parties where to write or call for more information on agent orange, and additional fact sheets and an agent orange digest.

VA cautioned, however, that any national broadcast campaign of public service announcements must be carefully handled. VA said that, because most such announcements are of 20- and 30-second duration, the message must be necessarily confined. According to VA, this has the potential of creating "unrealistic expectations." VA said that a national broadcast campaign could also create unwarranted fear and anxiety among veterans and dependents, especially since there is no conclusive scientific or medical evidence establishing a cause-and-effect relationship between exposure to agent orange and health problems in Vietnam veterans.

We agree that any public service announcement, whether national or local, must be carefully handled. However, the success of the Wood, Wisconsin, public service announcements in improving the medical center's relations with Vietnam veterans' groups demonstrates that effective announcements can be produced.

As stated on page 40, a VA study concluded that veterans' concerns may have been motivated by inaccurate and incomplete newspaper articles. Providing veterans carefully prepared factual data on agent orange and available VA services should not create such fear and anxiety among veterans.

Work with State veterans' affairs offices

VA agreed with our recommendation and said that it takes seriously its obligation to keep veterans informed of what is presently known about agent orange and what services are available to veterans. While VA's comments did not identify any actions it plans to take to work with State veterans' affairs offices, VA could use them to distribute informational material to concerned veterans. VA also stated that the lack of a list of veterans who served in Vietnam hinders its efforts to inform every veteran about agent orange. States, such as Minnesota, New Jersey, and Wisconsin, maintain such lists and could be helpful to VA in its efforts to locate concerned veterans and keep them informed.

CHAPTER 6

DENIAL OF DISABILITY CLAIMS MAY

PREVENT RETROACTIVE COMPENSATION

Although other forms of evidence are considered in adjudicating disability compensation claims, VA generally awards disability compensation only if evidence, particularly in the veteran's service medical records, shows that the veteran's disability was incurred in or aggravated during active military service. Almost half of the agent orange claims denied cited the lack of such evidence as the reason for denial. However, service medical records are unlikely to contain evidence of treatment for most health problems experienced by troops in Vietnam. As a result, veterans must establish that claimed disabilities were caused by exposure to agent orange during military service. The evidence needed to establish causation will not be available until ongoing epidemiological studies are completed. Because it may be several years before this evidence is available, the law could limit the amount of retroactive disability compensation veterans receive if claims are eventually awarded.

MOST AGENT ORANGE CLAIMS DENIED BECAUSE OF LACK OF EVIDENCE IN SERVICE MEDICAL RECORDS

About 93 percent of the disability claims adjudicated since April 1978 which veterans alleged to be agent orange related have been denied. Almost half were denied not because the claimed disability did not exist, but because there was no evidence in the veteran's service medical records or any other source that the claimed disability was diagnosed and treated during the veteran's service.

VA evaluates agent orange-related disability claims in the same manner as any other claim for a service-connected disability compensation. A claim is evaluated by a rating board based on a variety of evidence about the origin of the disability; however, according to the chief of the rating policy staff, the rating board relies primarily on data from veterans' service medical records in adjudicating claims.

In an April 1978 program guide on adjudicating agent orange disability claims, VA directed its regional offices to administratively disallow claims where the veteran claimed (1) exposure to herbicides but no disability or (2) genetic damage because of birth defects in his or her children, since title 38 U.S.C. makes no provision for such claims. Although the program guide did not provide specific guidance on adjudicating other claims, it did advise the regional offices that:

"Except for a skin condition known as chloracne, there are presently no firm data to incriminate the herbicides as causative agents of any other known category of disease or chronic symptom. * * *"

Thus, according to VA officials, agent orange claims were generally denied unless specific evidence in the veteran's service medical records showed that the claimed disability had occurred during his or her period of service.

Between April 1978 and July 1982, VA adjudicated 14,236 disability compensation claims which veterans alleged to be agent orange related and allowed service connection in 1,037 cases. According to VA, these cases were allowed for reasons not related to agent orange. Of the 1,037 cases allowed, 971 (about 94 percent) were for service-connected skin conditions. The other 66 claims (6 percent) were for cancer, psychiatric and neurological conditions, and various other disabilities.

As shown by the following table the existence of a disability was confirmed in 6,151 of the 13,199 claims denied, but the claim was denied because of the lack of evidence that the disability was incurred in or aggravated during the veteran's period of service.

<u>Reasons for denial</u>	<u>Number of claims</u>	<u>Percent of denied claims</u>
Claim did not allege a disability	3,268	25
Diagnosis of claimed disability not confirmed	3,780	29
Diagnosis of claimed disability confirmed by a physician, but no evidence that disability was service connected	<u>6,151</u>	<u>46</u>
Total claims denied	<u>13,199</u>	<u>100</u>

Claims for exposure to agent orange which did not allege a specific disability were generally administratively denied. The veterans were notified that for their claim to be fully adjudicated the claim must specify the disabilities that they believe were service related.

Because of the lack of scientific information on the long-term effects of exposure to agent orange, VA has stated that previously denied disability claims would be reviewed if the results of epidemiological studies show certain health problems were caused by agent orange exposure or service in Vietnam. However, according to VA, the law (38 U.S.C. 3010(g)) limits retroactive compensation to 1 year prior to the review for veterans whose claims are eventually awarded.

EVIDENCE OF SERVICE CONNECTION NOT
LIKELY TO BE FOUND IN SERVICE
MEDICAL RECORDS

Former medical personnel who served in Vietnam and officials from the Department of Defense and the Department of the Army advised us that service medical records were not well maintained in Vietnam. As a result, evidence that a veteran was treated for a particular health problem during service may not be entered in the veteran's service medical records.

According to former medical personnel in Vietnam, treatment for minor health problems incurred in the field, such as skin rashes, headaches, nausea, or other problems not requiring hospitalization, was generally provided at a battalion aid station or by a medical aidman or corpsman. Because troops were generally moved around within the division's area of operation, medical records were kept by the medical battalion or medical facility at divisional headquarters, rather than with troops in the field.

Although Army regulations required that field medical records be maintained for each patient provided treatment, a former provincial public health advisor for the I Corps section of Vietnam told us that no medical records were kept to document the diagnosis and treatment of minor health problems, such as skin rashes, at the numerous field units or battalion aid stations he visited. A former Army nurse who served at an evacuation hospital in II Corps confirmed that service medical records did not document all treatments or medications provided in the field.

VA REQUIRED TO REPORT ON
AGENCY ACTIONS TO ADDRESS
EPIDEMIOLOGY STUDY RESULTS

The Veterans' Health Programs Extension and Improvement Act of 1979 (Public Law 96-151, Dec. 20, 1979) requires VA to conduct an epidemiological study of veterans exposed to agent orange and to report to the Congress on the study results within 2 years after approval of the study protocol. The Veterans' Health Care, Training and Small Business Loan Act of 1981 (Public Law 97-72,

Nov. 3, 1981) amended this requirement to require VA to publish in the Federal Register, within 90 days after reporting the study results to the Congress, what actions it proposed to take regarding VA programs based on the study results. The intent of this amendment, at least in part, was to insure that VA would promulgate regulations in a timely manner for adjudicating disability compensation claims based on the findings of the epidemiological study required by Public Law 96-151.

CONCLUSIONS

Although VA considers other forms of evidence in determining whether a claimed disability was incurred in or aggravated by a veteran's service, service medical records are the most influential evidence in adjudicating disability compensation claims. The unreliability of service medical records makes it difficult for a veteran to prove a disability is service connected. As a result, ongoing epidemiological studies are likely to be the primary source of evidence to show whether the disabilities were service connected.

Because it may take several years before epidemiological evidence is available, veterans may be denied retroactive disability compensation for several years between the time they filed their claim and when the claim is eventually awarded.

MATTERS FOR CONSIDERATION BY THE CONGRESS

Veterans whose agent-orange related disability compensation claims are eventually proven to be service connected based on the results of ongoing scientific studies could, according to VA, receive retroactive compensation limited to 1 year before reconsideration of their claims regardless of the length of time necessary to complete these studies or the date the claim was filed. The Congress should therefore consider whether 38 U.S.C. 3010(g) should be amended to extend the retroactive compensation period for agent orange-related disability claims to the date the initial claim was filed.

AGENCY COMMENTS AND OUR EVALUATION

VA believes that it is too early to consider amending 38 U.S.C. 3010(g) to extend the period of retroactive compensation for agent orange-related disability claims. According to VA, changing the law before the scientific uncertainties are resolved could create false expectations in veterans justifiably concerned over the issue. VA said that it believes it would be more appropriate to await the results of the ongoing or soon to commence scientific studies before making any recommendations for changes in the laws regarding the effective date of an award of disability compensation benefits.

VA's position is not without some merit. However, VA has asserted that previously denied disability claims would be reconsidered should scientific evidence become available and this no doubt has already created certain expectations among veterans. Under present law, however, according to VA, such claims, should they be approved, would be retroactive for only 1 year, rather than to the date the claim was filed. The question, it seems, is whether changing the law now would unduly raise expectations or provide assurances that the disability claims heretofore denied for lack of evidence would be handled equitably should additional scientific evidence become available. In our view, this matter is worthy of congressional consideration.

OBJECTIVES, SCOPE, AND METHODOLOGY

Since 1978, VA medical facilities have examined over 89,000 veterans concerned about the possible health effects of exposure to agent orange. Congressman Thomas Downey and Senator John Heinz requested that we determine

- whether VA medical facilities were adequately implementing herbicide screening procedures,
- whether appropriate tests were administered,
- what agent orange-related training was provided VA staff,
- whether VA had allocated adequate funds for the herbicide screening program,
- what VA was doing with the information obtained from examinations,
- why VA had not attempted an outreach program, and
- whether VA was equitably adjudicating agent orange-related disability compensation claims.

To accomplish these objectives, we visited 13 VA medical centers--Decatur (Atlanta), Georgia; Augusta (Forest Hills), Georgia; Birmingham, Alabama; New York City, New York; Northport, New York; East Orange, New Jersey; Chicago (Westside), Illinois; Hines, Illinois; Minneapolis, Minnesota; Pittsburgh (University Drive) Pennsylvania; Wilkes-Barre, Pennsylvania; Los Angeles (Wadsworth), California; and Long Beach, California. We also visited the New York outpatient clinic attached to the New York medical center. The medical facilities were selected to provide a geographic representation and to include facilities that had performed a large number of agent orange examinations. Selection of the medical facilities was discussed with VA officials who agreed that they were representative of other VA medical facilities.

At VA's Central Office in Washington, D.C., we interviewed officials in the Department of Medicine and Surgery, the Department of Veterans Benefits, the Office of the General Counsel, the Office of Planning and Program Evaluation, and the Office of Information Services, and we reviewed policies, procedures, and records pertaining to the agent orange examination program and registry, outreach efforts, and adjudication of agent orange-related disability compensation claims.

ASSESSMENT OF VA'S
EXAMINATION PROGRAM

To determine whether the exposure history, medical history, laboratory tests, and physical examination used in VA's agent orange examination were adequate for gathering information about the health of veterans exposed to agent orange, we interviewed researchers who have studied populations exposed to dioxin and other chemicals from the Centers for Disease Control, the National Institute for Occupational Safety and Health, and two university medical schools.

To assess each medical facility's agent orange program, we interviewed the environmental physicians responsible for the program, physicians who performed agent orange examinations, and physicians in dermatology and pathology departments on how the examinations were performed, what treatment was provided, whether they had received any special training, and their attitude toward the agent orange program. We also interviewed senior medical officials concerning how they monitored the program's implementation. In addition, we interviewed administrative staff concerning how information was processed for the agent orange registry, how agent orange inquiries were handled, and how agent orange examinations were scheduled.

At each facility we examined a random sample of examination records of veterans who had agent orange examinations between May 1, 1979, and December 31, 1980, to determine how thoroughly the examinations were documented. The following table shows the size of our universe and sample at the 13 medical centers and one outpatient clinic.

<u>Medical facility</u>	<u>Universe</u>	<u>Adjusted sample size (note a)</u>
Decatur (Atlanta)	268	101
Augusta (Forest Hills)	133	77
Birmingham	208	69
New York Medical Center	136	41
Northport	398	132
East Orange	867	101
Chicago (Westside)	210	87
Hines	260	90
Minneapolis	4,864	234
Pittsburgh (University Drive)	89	42
Wilkes-Barre	890	97
Los Angeles (Wadsworth)	195	73
Long Beach	210	95
New York outpatient clinic	162	52
Total	<u>8,890</u>	<u>a/1,291</u>

a/We originally selected 1,323 records for review, but we could not review 32 of them because they could not be located, had been transferred to another VA medical facility, or represented examinations performed before our sample period.

We reviewed the three parts to the examination data collection forms (exposure history, medical history, and physical examination) to determine whether each exposure and medical history question was answered and whether each part of the body or body system included in the physical examination was evaluated. The examination records did not always contain all three parts of the examination data collection form because the forms were missing or the folder indicated that the veteran did not complete the examination. The following table shows the actual number of exposure histories, medical histories, and physical examinations reviewed.

	<u>Part I-- exposure history</u>	<u>Part II-- medical history</u>	<u>Part III-- physical examination</u>
Number reviewed	1,280	1,258	1,243
Number missing	4	15	8
Number not completed	<u>7</u>	<u>18</u>	<u>40</u>
Total	<u>1,291</u>	<u>1,291</u>	<u>1,291</u>

The results were analyzed using standard statistical techniques.

To assess the services and information provided by VA in agent orange examinations, we sent a questionnaire to a stratified random sample of veterans who had agent orange examinations during 1980. Appendix II describes our survey design and sampling methodology.

We conducted a telephone survey of 112 VA medical facilities to determine whether VA medical facilities provided telephone callers information on (1) the uses and possible health effects of agent orange and (2) available VA services.

ASSESSMENT OF THE AGENT ORANGE REGISTRY

To determine whether the agent orange registry was serving its intended purpose, we interviewed VA officials and reviewed VA reports and records. At each medical facility we interviewed administrative personnel to determine how the coding sheets used to enter examination data into the registry were completed and monitored for accuracy and completeness. We also reviewed a random sample of the locator cards to determine whether they contained the name, complete address (street, city, State, and ZIP code), and social security number of veterans who had agent orange examinations.

ASSESSMENT OF VA
OUTREACH EFFORTS

To determine whether VA had an effective outreach program to advise veterans of available information and services, we interviewed VA officials and reviewed internal VA studies of outreach alternatives and legal requirements for VA outreach programs. We also determined the availability of VA's agent orange pamphlet at the VA medical facilities visited, and we conducted a telephone survey to determine whether medical facilities offered to send callers VA's agent orange pamphlet and told callers about the availability of VA's agent orange film. We also interviewed State officials from Minnesota, Wisconsin, and New Jersey and officials from several veterans' organizations that had undertaken outreach programs to determine how the programs were conducted and their results.

ASSESSMENT OF VA'S ADJUDICATION
OF AGENT ORANGE DISABILITY CLAIMS

To determine whether VA's policies for adjudicating agent orange-related disability compensation claims were consistent with statutory requirements, we interviewed VA officials and reviewed VA's reports and regulations.

To determine if medical problems experienced by troops in Vietnam which did not require hospitalization were documented in service medical records, we interviewed former service medical personnel and officials from the Department of Defense and the Department of the Army, and we reviewed Army records.

TECHNICAL DESCRIPTION OF GAO'SSURVEY AND SAMPLING METHODOLOGY

In June 1981, GAO sent a questionnaire to a random sample of veterans who had agent orange examinations at VA medical facilities during 1980 to determine what services and information VA provided and the veterans' satisfaction with VA's efforts. We sampled veterans examined in 1980 to (1) insure that the veterans' responses reflected the current status of the examination program and (2) minimize problems veterans might have in recalling the details of their examination.

This appendix contains a technical description of our survey design, pretesting of the questionnaire, selection of the sample, calculation of the effective universe and sample size, calculation of the nonresponse rate and sampling error, and validation of the questionnaire results.

QUESTIONNAIRE DESIGN

The questionnaire was designed to elicit the veterans' experiences and opinions about the agent orange examination. Specifically, we asked veterans

- why they went to VA,
- what information VA provided,
- what exposure and medical history questions they were asked,
- what parts of their body were examined,
- what laboratory tests and followup care VA provided,
- whether they received their test results,
- whether they had health problems diagnosed by VA, and
- how satisfied they were with the VA agent orange examination.

The questionnaire was reviewed by GAO's medical advisor, and VA's Office of Environmental Medicine.

PRETESTING THE QUESTIONNAIRE

Before the questionnaire was used, it was pretested with four veterans who had received agent orange examinations at the Washington, D.C., VA medical center. The group represented the various levels of literacy likely to be found in the population surveyed.

In the first phase of the pretest, the veterans completed a questionnaire as if they had received it in the mail. A trained GAO observer noted unobtrusively the time it took to complete each question and any difficulties the subject experienced. During the second phase a standardized procedure was used to elicit the subjects' description of the various difficulties and considerations encountered as they completed each item. The procedure used only nondirect inquiries to ensure that the subject was not asked leading questions.

Based on the results of the pretest, we revised the questionnaire to ensure that (1) the potential subjects could and would provide the information requested and (2) all questions were fair, relevant, easy to answer, and relatively free of design flaws that could introduce bias or error into the study results. We also tested to insure that the task of completing the questionnaire would not place too great a burden on the veteran.

SELECTING THE SAMPLE

The universe for our sample was a list of 16,146 veterans included in VA's agent orange registry who had examinations during 1980. The universe was stratified by determining in which of VA's 28 medical districts the veteran was examined and then dividing the medical districts into three groups or strata, based on the number of examinations conducted in the medical district during 1980. Group I included all districts performing over 1,000 examinations. Group II included districts with between 501 and 1,000 examinations, and Group III consisted of districts performing 500 or fewer examinations. The table below shows which medical districts were in each group.

<u>Group</u>	<u>Medical district</u>
I (over 1,000 examinations)	4, 14, and 18
II (501 to 1,000 examinations)	1, 2, 11, 16, 20, and 25
III (0 to 500 examinations)	3, 5, 6, 7, 8, 9, 10, 12, 13, 15, 17, 19, 21, 22, 23, 24, 26, 27, and 28

A proportional, stratified, random sample of 1,114 veterans was drawn to obtain an overall sampling error of ± 2.8 percent at the 95-percent confidence level. This sampling plan makes it possible to analyze the data in relation to each medical district group and to examine the experiences of the average veteran who had an agent orange examination at any VA medical facility during 1980. The following table shows the initial sampling design.

<u>Strata</u>	<u>Universe</u>	<u>Sample size</u>	<u>Percent of veterans sampled</u>
Group I	5,751	375	6.5
Group II	4,378	357	8.2
Group III	<u>6,017</u>	<u>382</u>	6.3
Total	<u>16,146</u>	<u>1,114</u>	6.9

The questionnaire was administered through the mail by a procedure which ensured the respondents anonymity. The data were collected between June and July 1981. A followup letter was sent to those who failed to respond 4 weeks after the initial mailing. Four weeks later a second followup letter was sent to those who still had not responded.

CALCULATING THE EFFECTIVE UNIVERSE AND SAMPLE SIZE

A total of 1,114 veterans were sent questionnaires. However, 102 cases were considered invalid sample units and deleted from the universe sample. Of the 102 invalid samples

--96 were undeliverable because the veteran was not at the address provided by VA,

--3 were not completed because the veteran was reported deceased, and

--3 were not completed because the veteran reported not having had a VA agent orange examination.

Hence, the actual sample and universe were smaller than those in the original plan. The following table shows the invalid sample units and the size of the adjusted universe used to calculate the new sampling error.

<u>Strata</u>	<u>Universe</u>	<u>Sample size</u>	<u>Invalid sample units</u>	<u>Adjusted universe (projected) estimates (note a)</u>	<u>Final sample size</u>
Group I	5,751	375	29	5,307	346
Group II	4,378	357	33	3,974	324
Group III	<u>6,017</u>	<u>382</u>	<u>40</u>	<u>5,387</u>	<u>342</u>
Total	<u>16,146</u>	<u>1,114</u>	<u>102</u>	<u>14,668</u>	<u>1,012</u>

$a / (\text{Final sample size} \div \text{initial sample size}) \times \text{universe}$.

Deleting the invalid sample units increased the overall sampling error to ± 3.0 percent at the 95-percent confidence level.

CALCULATING THE NONRESPONSE RATE AND SAMPLING ERROR

The overall nonresponse rate was about 12 percent. This rate increased the overall sample error from ± 3.0 to ± 3.19 percent. The sampling error for Group I was ± 5.3 percent; for Group II, ± 5.7 percent; and for Group III, ± 5.4 percent. The following table shows the response rate for each stratum.

<u>Strata</u>	<u>Final sample size</u>	<u>Usable returned questionnaires</u>	<u>Response rate</u> (percent)
Group I	346	316	91
Group II	324	272	84
Group III	<u>342</u>	<u>303</u>	89
Total	<u>1,012</u>	<u>891</u>	88

The average individual question nonresponse rate was 3 percent. This rate varied somewhat by the type of question. It was 5.8 percent for questions the physicians asked the veterans, 5.5 percent for questions about the laboratory tests, 2.9 percent for questions dealing with parts of the body examined, 2.2 percent for questions concerned with reasons for seeking the medical examination, and 1.5 percent for all other questions. This item nonresponse rate decreases our effective sample size from 891 to 864, resulting in a final effective sampling error of 3.22 percent, rather than 3.19 percent. Hence, there is only a 5 out of 100 chance that sample projections will be in error by more than 3.2 percent.

VALIDATING THE QUESTIONNAIRE RESULTS

The validation study was conducted by reviewing the examination records of a random sample of veterans examined at the VA medical facilities we visited and comparing the documentation in the examination record with the veterans' questionnaire responses. The questions we validated concerned exposure and medical histories, the physical examination, laboratory tests, and consultations with other VA physicians. We did not validate attitude and opinion questions.

To control against bias, a double blind data collection procedure was used. First, examination records were prepared by VA staff before the distribution of the questionnaires. Second,

veterans completing questionnaires for the validation study were not told that their responses would be used to validate the questionnaire.

Veterans responding to validation questionnaires were extended pledges of confidentiality, rather than anonymity, so we could compare the veterans' responses with documentation in their examination records.

Both samples were drawn independently from the same population with replacement using random techniques. By chance some cases appeared in both samples. Overlap cases were excluded from the validation survey because the respondents were pledged anonymity. This exclusion has little effect on the assumption of randomness because both inclusion and exclusion are chance events.

We sent validation questionnaires to 164 veterans. However, 26 were later deleted from the validation because they were also part of the survey sample. Thus, the actual validation sample size was 138. A total of 102 veterans (about 74 percent) returned a completed validation questionnaire. However, six had to be deleted because VA examination records for these veterans were incomplete. Thus, the validation was conducted on the remaining 96 questionnaires. The validation questionnaires had an 8-percent item nonresponse rate making the effective validation sample size 88, with a confidence limit of ± 10 percent at the 95-percent certainty level.

Veterans' responses to the questionnaire concerning the exposure and medical history and the physical examination they received did not closely match the evidence in the examination records. The veterans' questionnaire responses and the examination records differed about 39 percent of the time. We did not determine whether this difference was due to physician over-reporting in the examination records or veteran underreporting.

SURVEY RESULTS

This appendix shows how the 891 veterans who responded to our survey answered each question. For each question the percentage to the right of each alternative response is the proportion of the veterans answering that question who chose that particular response. The number of veterans who answered each question on each part of multiple questions, indicated by the letter n, equals the total number of questionnaire respondents (891) minus the number of veterans who did not respond to that particular question. For some questions the sum of the percentages is greater than 100 percent because the veteran could choose more than one alternative response.



U.S. GENERAL ACCOUNTING OFFICE SURVEY OF VETERANS WHO HAVE HAD AGENT ORANGE EXAMINATIONS

INSTRUCTIONS

This questionnaire is being sent to you because the U.S. Congress wants to find out first hand what happens to veterans when they go to a Veterans Administration medical center for an Agent Orange examination. Congress has asked the U.S. General Accounting Office (GAO) to conduct this survey. The General Accounting Office is responsible for reviewing all Federal agencies and activities and reports only to Congress. It is independent of the Veterans Administration and all other Federal agencies.

This questionnaire can be completed in about fifteen minutes. The questions can be answered quickly and easily by checking the answers or filling in the blanks which best describe your opinion or experiences. Throughout this questionnaire there are numbers printed within parentheses to assist us in coding your responses for the computer. Please disregard these numbers.

There is no information on the questionnaire that can identify you. It is just like a secret mail ballot. We have given you a post card with a number on it. Mail the card back separately. Do not return it with the questionnaire. This card goes to a different address and no one can match the number on the card with the questionnaire. The only purpose of this card is to tell us that you have returned the questionnaire so that we will not have to bother you with reminder notices.

Please complete and return the form in the self-addressed, stamped envelope marked "Questionnaire" within 10 days. We need your help since we cannot make a meaningful study of this subject unless we hear from you and others like you.

If you have any problems with the questionnaire, please call John Hansen at (202) 389-5281, GAO Headquarters, Washington, D.C. He will be happy to help you.

Thank you for your cooperation.

SCHEDULING THE MEDICAL EXAMINATION

1. Where was the V.A. medical center that you went to for your Agent Orange examination?
 Group I - 35.5; Group II - 30.5; Group III - 34.0 (1-4)
 _____ LL
 (City) (State)

2. About when did you have your V.A. Agent Orange examination?
 _____ (estimate month and year) (1-10)
 (Month/Year)

a/ 3. How satisfied or dissatisfied were you with the way the V.A. scheduled your Agent Orange examination? That is, were they pleasant; did they seem to know what they were doing; did they give you useful information; did you get an examination as soon as you wanted it; and was the examination date and time convenient for you? (Check one column for each row.)

a/ Percentages may not sum to 100 percent due to rounding.

		Very satisfied	Generally satisfied	Marginally satisfied	Generally dissatisfied	Very dissatisfied	Can't recall	
		1	2	3	4	5	6	
1. Pleasantness	n=884	26.4	32.6	19.9	9.4	10.4	1.4	(11)
2. Knew what they were doing	n=883	12.9	25.4	19.3	18.8	22.3	1.4	(12)
3. Gave useful information	n=877	7.1	10.4	14.3	21.2	45.4	1.7	(13)
4. Had exam as soon as you wanted it	n=874	27.0	32.7	16.0	7.2	15.9	1.1	(14)
5. Convenience of exam date and time	n=881	26.8	35.0	16.6	7.5	13.1	1.1	(15)

INFORMATION YOU RECEIVED FROM THE V.A. ABOUT AGENT ORANGE

4. Did you ask the V.A. for information about Agent Orange? (Check one.) n=885 ¹⁰⁴

- 1. Yes 74.7
- 2. No 16.7
- 3. Can't recall 8.6

5. Did the V.A. give you or tell you any information about Agent Orange? (Check one.) n=889 ¹⁰⁴

- 1. Yes 42.6 (CONTINUE)
- 2. No 55.0 (GO TO QUESTION 7)
- 3. Can't recall (GO TO QUESTION 7) 2.4

b/ 6. What information did the V.A. give you or tell you about Agent Orange? (Check all that apply.) n=379

- 1. What Agent Orange is 60.7 ¹⁰⁴
- 2. How Agent Orange was used 58.3 ¹⁰⁴
- 3. What may happen to your health if you were exposed to Agent Orange 32.5 ¹⁰⁴
- 4. What may happen to your children's health if you were exposed to Agent Orange 23.5 ¹⁰⁴
- 5. A copy of the pamphlet "Worried About Agent Orange?" 28.8 ¹⁰⁴
- 6. Other (please describe) 16.6 ¹⁰⁴
- 7. Can't recall 5.3 ¹⁰⁴

b/ Percentages represent the proportion of the 379 veterans who answered yes to question 5.

c/ Percentages sum to more than 100 percent because veterans could choose more than one response.

INFORMATION ABOUT YOUR HEALTH AND EXPOSURE TO AGENT ORANGE

7. Were you asked to answer the following questions about Agent Orange exposure? (Check one column for each row.)

QUESTIONS ASKED	10			104
	1	2	3	
1. How many times were you exposed to Agent Orange? n=879	67.2	18.1	14.7	104
2. How were you exposed to Agent Orange? n=876	75.0	14.8	10.2	104
3. When were you exposed to Agent Orange? n=876	80.0	10.4	9.6	104
4. For how long a time were you exposed to Agent Orange? n=874	59.5	20.7	19.8	104

8. Were you asked if you had been exposed to other harmful chemicals at any time during your life? (Check one.) n=888 ¹⁰⁴

- 1. Yes 39.6
- 2. No 40.9
- 3. Can't recall 19.5

c/ 9. Why did you go to the V.A. for an Agent Orange examination? (Check all the reasons that apply.) n=891

- 1. Skin problems 54.2 ¹⁰⁴
- 2. Liver and/or kidney problems 14.0 ¹⁰⁴
- 3. Spouse miscarriage 14.9 ¹⁰⁴
- 4. Tumors or growths 16.0 ¹⁰⁴
- 5. Birth defects in your children 16.6 ¹⁰⁴
- 6. Problems with your nerves 56.6 ¹⁰⁴
- 7. Other health problems (Please specify.) 46.5 ¹⁰⁴
- 8. Had no health problems but you were concerned about Agent Orange 13.0 ¹⁰⁴
- 9. Had no health problems but you wanted a complete physical examination 3.3 ¹⁰⁴
- 10. Other (Please specify.) 11.7 ¹⁰⁴

d/ 10. What health problems, if any, has a doctor, other than one at the V.A., told you that you have? (Check all that apply.) n=891

- 1. Skin problems 36.5 (111)
- 2. Liver and/or kidney problems 11.4 (102)
- 3. Tumors or growths 12.2 (103)
- 4. Birth defects in your children 10.7 (100)
- 5. Problems with your nerves 37.6 (101)
- 6. Other health problems (Please specify.)
33.6 (100)
- 7. Not told by another doctor that you had any health problems 25.9 (107)

11. Did the V.A. ask you if you had the following health problems during or since your service in Vietnam? (Check one column for each row.)

QUESTIONS ASKED	Yes No Can't Recall		
	1	2	3
1. Nervousness n=868	54.0	30.4	15.6 (100)
2. Headaches n=855	54.0	29.8	16.2 (101)
3. Numbness in arms, legs, hands, feet n=853	47.0	32.4	20.6 (100)
4. Infections n=839	42.0	34.7	23.3 (101)
5. Liver problems n=820	43.5	33.7	22.8 (102)
6. Weight loss n=835	50.0	31.3	18.7 (103)
7. Fatigue n=843	46.4	34.0	19.6 (104)
8. Skin problems n=861	66.0	22.9	11.1 (105)
9. Lung problems n=822	45.1	33.1	21.8 (106)
10. Changes in sex drive n=840	43.0	38.3	18.7 (107)
11. Sterility n=819	42.5	38.2	19.3 (108)
12. Birth defects in children n=834	51.9	33.2	14.9 (109)
13. Tumors, growths, or lumps n=830	47.2	33.9	18.9 (100)
14. Kidney problems n=831	44.3	32.8	22.9 (101)

THE PHYSICAL EXAMINATION

12. Did the V.A. examine the following parts of your body? (Check one column for each row.)

	n	Yes No Can't Recall		
		1	2	3
1. Eyes	n=875	59.2	31.8	9.0 (101)
2. Ears	n=872	67.0	25.5	7.5 (102)
3. Nose	n=864	54.5	35.5	10.0 (103)
4. Throat	n=869	64.2	27.8	8.0 (104)
5. Chest	n=874	86.4	9.0	4.6 (105)
6. Back	n=868	57.1	32.5	10.4 (106)
7. Neck	n=861	49.4	38.3	12.3 (107)
8. Head	n=862	45.3	41.4	13.3 (108)
9. Arm pits	n=856	36.1	48.6	15.3 (109)
10. Groin	n=871	66.3	26.6	7.1 (100)
11. Stomach	n=861	54.9	33.6	11.5 (101)
12. Arms	n=860	52.7	35.9	11.4 (102)
13. Legs	n=864	54.6	34.6	10.8 (103)
14. Feet	n=860	53.2	36.5	10.3 (104)
15. Hands	n=859	53.1	35.9	11.0 (105)
16. Skin	n=864	63.5	25.8	10.7 (106)
17. Reflexes	n=865	68.7	21.5	9.8 (107)
18. Other (Please specify.) n=90				
		70.0	10.0	20.0 (108)

d/ 13. What health problems, if any, did the V.A. tell you that you had? (Check all that apply.) n=891

- 1. Skin problems 26.2 (101)
- 2. Liver and/or kidney problems 3.9 (102)
- 3. Tumors or growths 6.2 (103)
- 4. Problems with your nerves 17.4 (104)
- 5. Other health problems (Please specify.)
19.1 (105)
- 6. Told you that you had no health problems 20.2 (106)
- 7. Told you nothing about your health 30.9 (107)
- 8. Can't recall 1.7 (108)

d/ Percentages sum to more than 100 percent because veterans could choose more than one response.

14. Did a second V.A. doctor examine you? (Check one.) *n*=879

- 1. Yes 23.2
- 2. No 74.5
- 3. Can't recall 2.3

15. Did a V.A. skin doctor examine you? (Check one.) *n*=880

- 1. Yes 21.6
- 2. No 61.0
- 3. Don't know what kind of doctor examined you 15.8
- 4. Can't recall 1.6

LABORATORY TESTS

16. Did the V.A. give you the following laboratory tests as part of your Agent Orange examination? (Check one column for each row.)

LAB TESTS		Yes	No	Can't recall
		1	2	3
1. Blood sample	<i>n</i> =878	89.7	7.1	3.2
2. Urine specimen	<i>n</i> =871	82.5	12.4	5.1
3. Chest X-ray	<i>n</i> =875	78.8	14.7	6.5
4. Other X-ray	<i>n</i> =776	16.5	70.9	12.6
5. Sperm sample	<i>n</i> =827	8.1	89.5	2.4
6. Skin sample	<i>n</i> =826	6.7	89.5	3.8
7. Other (Please specify.)	<i>n</i> =77			
		32.5	57.1	10.4

17. If you had lab tests done, did you get the results of these tests? (Check one.) *n*=871

- 1. Yes 25.7 (CONTINUE)
- 2. No 65.7 (GO TO QUESTION 20)
- 3. Had no lab tests done 3.9 (GO TO QUESTION 20)
- 4. Can't recall (GO TO QUESTION 19) 4.7

e/ 18. If you had lab tests done and got the results, when did you get the results? (Check one.) *n*=220

- 1. The same day the tests were done 13.6
- 2. In 2 weeks or less from when the tests were done 25.0
- 3. From 2 to less than 4 weeks from when the tests were done 29.6
- 4. 4 weeks or more from when the tests were done 23.2
- 5. Can't recall 8.6

f/ 19. If you had lab tests done, did the V.A. tell you that they would only give you the results if something were wrong? (Check one.) *n*=266

- 1. Yes 27.1
- 2. No 45.1
- 3. Can't recall 27.8

e/Percentages represent the proportion of the 220 veterans who responded yes to question 17.

f/Percentages represent the proportion of 266 veterans who responded yes or can't recall to question 17.

REASONS FOR HAVING AN AGENT ORANGE EXAMINATION

g/ 20. Listed below are some reasons why you may have gone to the V.A. for an Agent Orange examination. For each reason which was a concern to you, how satisfied or dissatisfied were you with what the V.A. did for you? (Check one column for each row.)

g/ The number of respondents (n) for each reason in question 20 was calculated using the overall item non-response rate for the question (2.2 percent), rather than the item non-response rate for each reason. Percentages may not sum to 100 percent due to rounding.

REASONS		Very satisfied	Generally satisfied	Marginally satisfied	Generally dissatisfied	Very dissatisfied	Total % (n)
		1	2	3	4	5	
1. I wanted to be examined for health problems I had which I believed were caused by exposure to Agent Orange	n=888	4.3	7.3	11.3	13.4	35.2	28.5 (4)
2. I wanted to find out if I had served in a place in Vietnam where I could have been exposed to Agent Orange	n=888	5.7	7.0	7.2	10.2	30.5	39.3 (4)
3. I wanted to be examined and/or tested to see if I had been exposed to Agent Orange	n=888	6.1	9.8	13.5	12.8	32.1	25.7 (4)
4. I wanted to be examined and/or tested to see if I had any health problems caused by Agent Orange	n=889	7.4	10.1	14.4	17.9	37.6	12.6 (4)
5. I wanted to find out what could happen to my health if I had been exposed to Agent Orange	n=888	4.7	7.4	9.1	15.4	43.1	20.2 (4)
6. I wanted to know if Agent Orange could affect the health of my children	n=888	4.7	6.1	8.3	12.4	42.2	26.2 (4)
7. I wanted a free medical examination	n=885	2.8	2.6	3.4	2.4	6.7	82.1 (4)
8. Other reasons (Please specify)							
	n=806	0.7	0.2	0.2	0.4	5.8	92.7 (4)

AFTER THE EXAMINATION

h/ 21. For what reasons, if any, were you asked to come back to the V.A.? (Check all that apply.) n=89

- 1. Laboratory tests 16.2 (5)
- 2. To see another doctor 16.5 (5)
- 3. For a follow-up examination 14.9 (5)
- 4. To pick up medicine 6.6 (5)
- 5. Other (Please specify) 9.8 (5)
- 6. Was not asked to come back 53.9 (5)
- 7. Can't recall 1.5 (5)

22. How long did you spend at the V.A. medical center on the day of your examination, from the time you arrived to the time you left? (Check one.) n=871 (5)

- 1. Less than 1 hour 8.0
- 2. From 1 hour to less than 2 hours 20.0
- 3. From 2 hours to less than 3 hours 24.7
- 4. From 3 hours to less than 4 hours 16.3
- 5. 4 hours or more 29.3
- 6. Can't recall 1.7

h/ Percentages sum to more than 100 percent because veterans could choose more than one response.

23. How satisfied or dissatisfied were you with the following aspects of your V.A. Agent Orange examination? (Check one column for each row.)

ASPECTS OF THE EXAMINATION			Very satisfied	Generally satisfied	Marginally satisfied	Generally dissatisfied	Very dissatisfied	
			1	2	3	4	5	
1	The interest the people at the V.A. took in your health	n=877	9.0	19.5	22.5	19.8	29.2	(09)
2	The thoroughness of the questions the people at the V.A. asked you	n=875	7.2	20.7	24.7	21.5	25.9	(08)
3	The clearness of the questions the people at the V.A. asked you	n=874	11.7	26.8	23.5	18.1	20.0	(01)
4	The opportunity you were given to ask questions	n=877	11.3	20.1	19.4	19.0	30.2	(03)
5	The completeness of your Agent Orange physical examination	n=866	8.7	15.0	18.9	19.2	38.2	(03)
6	The number of lab tests the V.A. gave you	n=852	7.7	20.8	22.2	18.2	31.1	(04)
7	The amount of information you learned from the V.A. about Agent Orange	n=876	3.4	5.1	11.1	20.5	59.8	(03)
8	The amount of information you learned from the V.A. about your own exposure to Agent Orange	n=871	2.5	5.3	9.2	18.5	64.5	(04)
9	The amount of time the V.A. spent on your entire Agent Orange examination	n=866	6.4	15.9	20.9	16.6	40.2	(07)

ADDITIONAL COMMENTS

24. If you would like to give other information or comment on your V.A. Agent Orange examination, or on the questions above, please write your views below. n=891

70.6

(08)

SUMMARY OF SAMPLE OF
EXAMINATION RECORDS

Referrals to Specialty Clinics
from Agent Orange Examinations

(Based on 1,243 examination records)

<u>Specialty clinics</u>	<u>Number of referrals</u>
Dermatology	483
Urology (sperm count)	136
Psychiatry	70
Cardiology	67
Eye, Ear, Nose, and Throat	66
X-ray	50
Neurology	50
GU and GI	36
Orthopedics	28
Medical	25
Surgery	20
Other referrals (note a)	<u>38</u>
Total referrals	<u>1,069</u>

a/Other referrals include alcohol and drugs, stool tests, dental, dietary, proctology, endocrinology, hematology, nuclear medicine, pulmonary, podiatry, outpatient, pathology, social work, and physical therapy.

Percentage of Examination Records
Which Indicated That Required
Medical History Questions Were Asked

(Based on 1,258 examination records)

<u>Medical history</u> <u>questions</u>	<u>Percent of records</u> <u>in which response</u> <u>was documented</u>
Nervous system	40
Immune system	28
Liver	75
Kidneys	73
Thyroid	27
Adrenals	19
Skin	71
Lungs	52
Altered sex drive	36
Sterility	92
Birth defects	77
Neoplasia	91
Pregnancy difficulties	70
Gonads	45
Blood forming system	73

Average Number of Medical History
Questions Documented in Examination
Records Sampled at Each Facility

<u>VA medical facilities</u>	Average number of medical history questions documented (note a)
Augusta, Ga.	11
Birmingham, Ala.	11
Decatur (Atlanta), Ga.	11
Hines, Ill.	7
Minneapolis, Minn.	10
Chicago (Westside), Ill.	6
Long Beach, Calif.	7
Los Angeles (Wadsworth), Calif.	6
New York, N.Y.	8
New York (outpatient clinic), N.Y.	7
East Orange, N.J.	10
Northport, N.Y.	6
Pittsburgh (University Drive), Pa.	7
Wilkes-Barre, Pa.	14

a/Examining physician is required to ask 15 medical history questions.

Percentage of Examination Records Which Indicated
That Each Body Part or System Was Examined

(Based on 1,243 examination records)

<u>Body part or system</u>	<u>Percent of records indicating that part or system was examined</u>
Appearance/mental status	80
Head/neck	94
Eyes	92
Ears	90
Nose	89
Mouth	73
Throat	90
Teeth	72
Lymphatics	78
Chest	85
Lungs	96
Cardiovascular	95
Abdomen	95
Hernia	79
Genitalia	77
Rectum	60
Prostate	54
Back	59
Extremities	84
Neurological	85
Skin	83

Average Number of Body Parts and
Systems Documented in Examination
Records Sampled at Each Facility

<u>VA medical facility</u>	Average number of body parts or systems documented (note a)
Augusta, Ga.	20
Birmingham, Ala.	19
Decatur (Atlanta), Ga.	13
Hines, Ill.	18
Minneapolis, Minn.	18
Chicago (Westside), Ill.	17
Long Beach, Calif.	18
Los Angeles (Wadsworth), Calif.	16
New York, N.Y.	12
New York (outpatient clinic), N.Y.	16
East Orange, N.J.	17
Northport, N.Y.	15
Pittsburgh (University Drive), Pa.	17
Wilkes-Barre, Pa.	20

a/Physician is required to describe 21 body parts and systems.

Office of the
Administrator
of Veterans Affairs

Washington, D.C. 20420



October 1, 1982



Mr. Gregory J. Ahart
Director, Human Resources Division
U.S. General Accounting Office
Washington, DC 20548

Dear Mr. Ahart:

The August 6, 1982, draft report, "Improvements Needed in VA's Efforts to Assist Veterans Concerned About Agent Orange." has been reviewed. The report indicates that the General Accounting Office (GAO) reviewed records of examinations conducted between May 1979 and December 1980 and sent questionnaires to veterans who were examined during 1980. By citing old data in conjunction with more current Veterans Administration (VA) programs and initiatives, a conclusion could be reached that the VA's efforts have been ineffective in addressing the concerns of Vietnam veterans. A more proper conclusion is that the VA recognized many of the concerns identified and has taken appropriate corrective measures. An example of this is found in the reported statistic that only 29 percent of the veterans examined in 1980 received the pamphlet, "Worried About Agent Orange?" The report fails to note that the pamphlet was not available for distribution until the summer of 1980 and was available in the medical centers only during the last 4 or 5 months of the year.

The report documents the veterans' dissatisfaction with the health examination and GAO criticizes the VA for unsatisfactory and incomplete examinations. Dissatisfaction arises when expectations are not met and the greatest dissatisfaction ensued when the veteran wanted to know whether he had health problems due to agent orange, what could happen to his health, and what could happen to his children. These three questions are unanswerable even today by any examination. The report partially recognizes this and tasks the VA with better informing the patients of the examination's limitation.

The methodology GAO used to assess the adequacy of the physical examination is questionable and the conclusions are based on a lay person's perception about an examination performed 6 to 12 months earlier. It is difficult for nonhealth professionals to evaluate the performance of health professionals. Much of what is done during a physical examination is inapparent to the person being examined. As an example, a physician need not touch a person with normal skin to decide that there is no significant skin condition; examination can be well done by inspection, or looking, alone. Yet 25.8 percent of veterans reported that the skin was not examined. A related limitation occurs when a person evaluates the taking of a medical history that occurred 6 to 12 months earlier. Many persons are unable to recall whether specific questions or sets of questions were asked among the many topics covered. The physician can ask about nervousness or fatigue, for example, without using such terms, and the questions asked may not be identified with the items listed in the questionnaire.

GAO note: The page references in this appendix may not correspond to the page numbers in the final report.

Confusion can also arise concerning the information given the veteran after the examination. Physicians customarily say, "Your laboratory tests were all normal," and consider this a report of the clinical chemistry to the veteran who forgets such a short phrase and reports, as 65.7 percent did, that they "did not get the results of these tests." A veteran's report of unsatisfactory physician performance is more valuable as an indicator of the veteran's satisfaction than of the quality of the examination.

The report indicates some appreciation of this fact and the GAO team examined medical records to evaluate the professional performance of the examiners. The record audits determined the quality of the recording rather than of the examination. The latter seems more important for the veterans, but is also more difficult to evaluate and probably cannot be accomplished by persons who are not qualified health care professionals.

The report implies an acceptance of the assumption that there is more knowledge available about ill effects due to herbicides than is being used by the VA. For example, it is noted that only 10 percent of veterans were given information about what could happen to their children's health, a statement apparently based on the replies to the questionnaire. Since no one has demonstrated that exposure of a man to agent orange has any effect on children he fathers thereafter, the physician usually will not raise the issue with a veteran who does not specifically ask about it. To do so would needlessly make the veteran anxious without helping him in any way. Since chloracne is the only established relatively persistent effect of exposure to an ingredient of agent orange, the physician finds it difficult to offer any specific advice in response to veterans' inquiries about possible ill effects. Veterans may construe the statement, "We have no medically or scientifically accepted evidence that agent orange causes your disease," as failure to inform them.

GAO also suggests that VA examiners would be more effective if they had "sufficient knowledge of the potential symptoms of dioxin exposure." The VA would focus on specific body systems as suggested if there were more information on the potential symptoms of exposure to agent orange. Unfortunately, the information necessary to do so is not available anywhere.

The enclosure addresses the recommendations as they appear in the report.

Sincerely,



ROBERT P. NIMMO
Administrator

Enclosure

**VA'S COMMENTS ON THE GAO AUGUST 6, 1982, DRAFT REPORT,
"IMPROVEMENTS NEEDED IN VA'S EFFORTS TO ASSIST VETERANS
CONCERNED ABOUT AGENT ORANGE"**

GAO recommends that the Administrator, through the Chief Medical Director:

- Require VA medical facilities to include the agent orange examination program in the facilities' systematic internal review process.

I agree, but the systematic internal review program leaves to each medical center the selection of specific facility activities to review at any one time. However, the systematic external review program (SERP) reviews the quality assurance of each center's ambulatory care program. In the future, the SERP medical team member who surveys ambulatory care will review the agent orange program, using detailed criteria being developed. This will accomplish the intent of this recommendation.

- Require environmental physicians to review all examination records to insure that examinations are thorough and documented.

This recommendation is already implemented. The January 14, 1981, Department of Medicine and Surgery (DM&S) Circular 10-81-12 directed environmental physicians to advise veterans of the results of their examinations. This was further stressed in a February 11, 1981, Chief Medical Director's Information Letter, IL 10-81-5. Environmental physicians were directed to inform veterans of the positive or negative findings of their examinations. The physician's prior review of each medical record is implied in these directives.

- Direct VA physicians to document all findings for every factor described in VA agent orange program circulars for each examination.

I do not concur. The VA is revising the agent orange examinations reports and any specific directions concerning documentation are better given at the time the new procedures are distributed.

- Reemphasize to VA medical facilities the importance of providing examinations in a timely manner.

I believe the problem of excessive delays in agent orange examination schedules no longer exists. For the past two years, the VA has continually emphasized the need for prompt examinations. For the past 17 months, each facility has been reporting its monthly backlog and the number of agent orange examinations performed. From May through July 1982, only one facility reported a backlog of 50 or more scheduled examinations. This facility is Anchorage, Alaska, where there is a regional office but no hospital or clinic, and where it is difficult to obtain contract physicians to examine the waiting veterans. Other VA facilities have short waiting lists and almost always perform examinations within 30 days after application.

- Direct VA medical facilities to insure that examining physicians are familiar with available information on agent orange and that they provide this information to all veterans examined.

I agree, and examining physicians will be kept informed of all agent orange information as it becomes available. This will be accomplished through national conferences, information mailings, and telephone conferences. I do not agree, however, that this information should be provided to all veterans examined as it would serve no useful purpose. Examining physicians should discuss agent orange matters with the veterans as questions are raised, not as a routine to be followed as part of each examination.

- Discontinue the computerized agent orange registry, and maintain a list of veterans who have had agent orange examinations.

I do not concur in this recommendation. The agent orange registry is the most extensive list of Vietnam veterans concerned about agent orange. The registry program is an important mechanism for assisting the VA in detecting significant health trends in the Vietnam veteran population, which may differ from that of the general population. Descriptive information generated from the registry enables the VA to review those areas requiring more indepth medical/scientific analysis. It also serves as an index to the medical record of the examination where more detailed information can be sought as needed.

- Revise the exposure history form, and use the standard VA physical examination and medical history forms to gather more thorough information during agent orange examinations.

I concur. The March 19, 1981, DM&S Circular 10-81-54 stipulated that standard physical examination forms (VAF 10-7978 or SF 506) be used to document the physical examination. This circular is being revised and will include instructions on the use of physical examination forms. The exposure history forms (VAF 10-20681 and VAF 10-9009) used in the agent orange examination process are also being revised. It is anticipated that these revised forms will be available to VA health care facilities in December 1982.

- Direct VA medical facilities to inform veterans seeking agent orange examinations of the examination's limitations.

I concur. It should be noted that among other activities, the VA prepared and widely distributed the pamphlet, "Agent Orange Information for Veterans Who Served in Vietnam - Questions and Answers." This pamphlet specifically addresses the limitations of the examination. During education conferences on agent orange in September 1979 and May 1980, environmental physicians were instructed to explain the purpose of the examination process to veterans receiving examinations. In meetings with the administrative staffs of veterans' organizations, the VA explained the nature and limitations of the examination. The media was also informed of the intent, nature, and limitations of the examination. During an August 13, 1982, nationwide conference call, the health care staff was instructed to define the limitations of the agent orange examinations. These instructions will be outlined in a Chief Medical Director letter scheduled for publication this month.

- Develop and analyze statistics on the kinds of skin problems, tumors, and birth defects identified in agent orange examinations, and make this information available to veterans.

I do not concur because the intent of this recommendation, as stated, is not clear. Information gained by the development and analysis of such statistics cannot be used to compare the prevalence of illnesses or disabilities reported by Vietnam veterans with that of the general population because the veterans examined are a self-selected population and more prone to report real or perceived illnesses or disabilities. Any statistical report of prevalence, based on registry data, implies a much greater prevalence among all Vietnam veterans than is actually the case and, therefore, might serve to unduly alarm veterans without providing useful information.

- Emphasize to VA medical facilities the importance of sending tissue samples taken from veterans who served in Vietnam to the Armed Forces Institute of Pathology.

I concur. The VA continues to emphasize the importance of the special registry at the Armed Forces Institute of Pathology (AFIP) and will continue to urge VA medical facilities to send pathological material obtained from any Vietnam veteran. A Chief Medical Director's letter reemphasizing the need to provide tissue samples to the AFIP will be released this month. In addition, this issue was addressed during an August 13, 1982, nationwide conference call with VA field staff. Earlier VA activities relating to the AFIP include:

1. A series of Circulars (10-78-234, 10-79-239, 10-80-229, and 10-82-37) was issued directing all VA medical centers to send this material to the AFIP. On March 16, 1981, and March 22, 1982, this matter was discussed during nationwide conference calls with environmental physicians, chiefs of staff, and other key officials at all VA medical centers.
2. Transcripts of meetings of the VA Advisory Committee on Health-Related Effects of Herbicides are sent to all environmental physicians.
3. The AFIP registry was publicized in the July 1981 issue of Agent Orange Bulletin.
4. Earlier poor cooperation in submitting tissue samples was due in large part to the lack of an indicator for in-country Vietnam service in VA medical records. This deficiency was corrected by DM&S Circular 10-82-128.

- Hasten the development of a monograph on agent orange's potential for causing birth defects.

On June 30, 1982, I approved funds for a monograph series. One of the series, "Birth Defects/Genetic Screening," was funded for Fiscal Year 1982. The VA is now seeking a consultant who will prepare that monograph which has a December 1983 completion date.

--Direct VA medical facilities to provide available information to veterans concerned about birth defects, or refer veterans to genetic counseling services for such information.

I concur, and this recommendation has been implemented. On September 18, 1981, the VA forwarded a copy of the March of Dimes Birth Defects Foundation publication, "Birth Defects/Genetic Services," to all environmental physicians. This publication provides an international directory of genetic counseling services. The physicians have been instructed to refer veterans to one of these facilities when they request special genetic testing and counseling.

--Direct VA medical facilities to follow up with all veterans examined before January 1981 to insure that they have been provided their examination results.

I do not agree that veterans should be provided with the results of examinations performed before January 1981 because of their greatly diminished usefulness. In fact, receiving belated results 1 or 2 years after examination could unduly alarm veterans. The results of agent orange examinations are permanently maintained in the veterans' medical records and are available to veterans upon request.

--Direct all VA medical facilities to offer to send the agent orange pamphlet to all telephone callers interested in information about agent orange, and advise callers when and where they can see the agent orange film.

I concur. This recommendation is being implemented. The pamphlet, "Worried About Agent Orange?" is now out of date and out of print. However, three new pamphlets were distributed early this year and cover a broad spectrum of information on this important issue. More will be published and made available to all VA facilities. During August and September conference calls, VA medical centers were advised to use the agent orange pamphlets and film. These calls will be followed by a Chief Medical Director's letter reminding them of the recommended actions.

--Use public service announcements to advise veterans of VA agent orange services.

I concur. The VA is using public service announcements (PSA's) to provide an information and education program for concerned Vietnam veterans and their families. An automated mailing list was developed for the agent orange registry and in June, over 80,000 letters were mailed to veterans on the registry, along with 2 newly published information pamphlets. Mailings will continue as additional publications are issued.

Other outreach efforts will include, but not be limited to, a display and franked card return mailers at all VA facilities, print and broadcast PSA's directing interested parties where to write or call for more information on agent orange, and additional fact sheets and an agent orange digest.

Any national broadcast campaign of PSA's must be carefully handled. Because most PSA's are of 20- and 30-second duration, the message must be necessarily confined. This has the potential of creating "unrealistic expectations" which GAO is concerned about. A national broadcast campaign could also create unwarranted fear and anxiety among veterans and dependents, especially since there is no conclusive scientific or medical evidence establishing a cause-and-effect relationship between exposure to agent orange and health problems in Vietnam veterans.

--Work with State veterans affairs offices to advise veterans of available VA agent orange services.

I concur, and assure you that the VA takes seriously its obligation to keep veterans informed of what is presently known about agent orange and what services are available to veterans. Information material, including news releases, is distributed to VA facilities, to veterans organizations, to the media, the Congress, and upon request. All testimony before the Congress by the VA and other agencies is made part of public record. VA officials deliver speeches, participate in public seminars, news media interviews, and other forums dealing with agent orange. The VA has produced a video tape for showing, as appropriate, internally and externally. Although attempts are made to inform every Vietnam veteran about agent orange, the examinations, and provisions for treatment, it should be noted that the VA has an especially difficult task because there is no list of the 2.4 million veterans who actually served in Vietnam.

GAO also recommends that:

--the Congress consider whether 38 U.S.C. 3010(g) should be amended to extend the period of retroactive compensation for agent orange-related disability claims to the date the claim was filed.

I believe this recommendation is premature. At present, the best available scientific evidence fails to indicate that exposure to agent orange or other herbicides used in Vietnam has caused any long term health problems for veterans. A number of research efforts are underway, or will soon commence, that will attempt to shed more light on this difficult question. I believe it is more appropriate to await the results of the various studies before making any recommendations for changes in the laws regarding the effective date of an award of disability compensation benefits. Changing the law before the scientific uncertainties are resolved could create false expectations in veterans justifiably concerned over the issue.

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