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VA HEALTH CARE

Better Integration of Services Could Improve Gulf War Veterans' Care



**Health, Education, and
Human Services Division**

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The Honorable Cliff Stearns
Chairman, Subcommittee on Health
Committee on Veterans' Affairs
House of Representatives

The Honorable Christopher J. Dodd
United States Senate

Almost 700,000 members of the U.S. military served in Southwest Asia during the Persian Gulf War. Some of these Gulf War veterans subsequently reported an array of symptoms that they attributed to their service in the Gulf, including fatigue, skin rashes, headaches, muscle and joint pain, memory loss, shortness of breath, sleep disturbances, gastrointestinal conditions, and chest pain. The absence of data on the health status of service members who served in the Gulf War—including both baseline information and postdeployment status information—has, however, greatly complicated the epidemiological research on the causes of Gulf War illnesses.¹

In 1992, the Department of Veterans Affairs (VA) established the Persian Gulf Registry Health Examination Program primarily to assist Gulf War veterans in gaining entry into the continuum of VA health care services by providing them with a free physical examination and by acting as a health screening database. As of March 1998, about 68,000 Gulf War veterans had participated in VA's Registry program. In 1994 the Department of Defense (DOD) implemented a clinical evaluation program similar to VA's in which about 33,000 military personnel have participated.

This letter responds to your interest in VA's provision of health care services to Gulf War veterans. We provided preliminary information on the results of our review work in testimony before the Subcommittee on June 19, 1997, and in a letter to the Senate Committee on Veterans' Affairs on April 20, 1998. This is the final report on the results of our review of (1) the number of veterans VA and DOD report as suffering from Gulf War-related illnesses and the criteria used to identify these illnesses; (2) how VA diagnoses, counsels, treats, and monitors Gulf War veterans for the health problems they report; and (3) Gulf War veterans' satisfaction with the

¹Defense Health Care: Medical Surveillance Improved Since Gulf War, but Mixed Results in Bosnia (GAO/NSIAD-97-136, May 13, 1997).

health care they receive from VA. A listing of GAO products addressing various Gulf War issues appears at the end of this report.

To evaluate VA's diagnosis, counseling, treatment, and monitoring of Gulf War veterans, we met with VA officials responsible for managing and implementing the Persian Gulf Registry program and reviewed legislation, program guidance, program operating procedures, and management reports. We conducted case studies at six VA medical facilities, during which we talked with program staff members, observed program operations, and reviewed a sample of veterans' medical records to identify the types of services provided. We also reviewed reports issued by others, including the National Academy of Science's Institute of Medicine (IOM). IOM recently issued a report on its assessment of the adequacy and implementation of VA's Persian Gulf Registry protocol as a diagnostic tool for assessing the medical needs of Persian Gulf veterans.² We did not attempt to determine the appropriateness of the tests, evaluations, and treatment provided to these veterans, but rather examined whether VA followed its guidelines and procedures in caring for Gulf War veterans. To determine veteran satisfaction with VA's Gulf War health care services, we talked with and reviewed correspondence from Gulf War veterans we contacted, or who contacted us, and surveyed a nationwide random sample of veterans who participated in the Persian Gulf Registry program during 1996 and 1997. Further details of our scope and methodology are in appendix I. We did our work between March 1997 and May 1998 in accordance with generally accepted government auditing standards.

Results in Brief

While the number of Persian Gulf War veterans who participated in the military operations known as Desert Shield and Desert Storm is well established at almost 700,000, the number who actually suffer, or believe they suffer, from illnesses related to their Gulf War service remains uncertain 7 years after the war. The primary difficulty in assessing the impact of such illnesses lies in the fact that the link between the veterans' symptoms and the causes of those symptoms has not yet been identified scientifically. Thus, while some data on Gulf War veterans' symptoms have been collected and categorized, it is not yet known whether the symptoms reported are the direct result of the veterans' Gulf War service. Combined, VA and DOD report, however, that about 100,000 Gulf War veterans have requested Registry examinations because of war-related health concerns.

²National Academy of Science, Institute of Medicine, Adequacy of the VA Persian Gulf Registry and Uniform Case Assessment Protocol (Washington, D.C.: National Academy Press, 1998).

In response to a variety of symptoms and illnesses reported by Gulf War veterans, VA implemented a program in 1992 to help them receive VA health care. This free diagnostic and referral process has two stages: (1) an initial medical history and a physical examination with basic laboratory testing and (2) if needed, further evaluation through specialist consultation and additional symptom-specific testing. Currently, 212 VA facilities offer the Registry program to Gulf War veterans. However, VA's guidance regarding the evaluation and diagnosis of Gulf War veterans is not being consistently implemented in some of its medical facilities. More specifically, some physicians do not perform all of the symptom-specific tests recommended by VA, which could result in some veterans not receiving a clearly defined diagnosis for their symptoms. Moreover, while VA records show that thousands of veterans remain undiagnosed, only about 500 veterans have been sent to referral centers for additional evaluations, as recommended by the Registry guidance. In addition, mandated personal counseling of veterans often does not occur, and the form letters sent to veterans at the completion of the Registry examination do not always sufficiently explain test results or diagnoses, often leaving veterans frustrated and confused.

VA's guidance provides that Registry physicians are responsible for giving veterans medical examinations and necessary treatment. However, VA has not fully developed and implemented an integrated diagnostic and treatment program to meet the health care needs of Gulf War veterans. For example, in two of the six facilities we visited, veterans received ongoing treatment from the Registry physician or a select group of health care providers who are familiar with the illnesses experienced by Gulf War veterans. However, in four of the six facilities we visited, veterans who were given the Registry examination were no longer treated by the Registry staff but were instead referred to primary care physicians or teams for treatment. Primary care physicians typically do not specialize in the care and treatment of Gulf War veterans but rather are responsible for serving the general veteran population. In addition, efforts to monitor the clinical progress of Gulf War veterans have been limited. VA officials acknowledge that such efforts are critical but have only recently taken preliminary steps to begin tracking Gulf War veterans' health and treatment outcomes.

VA's diagnostic and treatment implementation problems are reflected by Gulf War veterans' general dissatisfaction with their health care. On the basis of our nationwide survey, over one half of the veterans who received the Registry examination in 1996 and 1997 were dissatisfied with the examination they received. Specifically, veterans were dissatisfied with

the thoroughness of the exam, explanations regarding the need for certain tests, and feedback explaining their test results and diagnosis. Furthermore, about half of the veterans responded that VA did not provide any of the treatment they believed they needed for their Gulf War-related health problems. Similarly, VA's recent National Customer Feedback Center survey of Gulf War veterans who received ambulatory care from fiscal years 1992 through 1997 reported that almost one-third of Gulf War veterans responding rated their VA care as fair to poor.

Our work suggests the need for VA to develop and uniformly implement a health care process that focuses on the special needs of Gulf War veterans. This process should provide for the integration of diagnostic services, treatment of symptoms and illnesses, evaluation of treatment effectiveness, and periodic reevaluation of those veterans whose illnesses remain undiagnosed.

Background

VA's efforts to assist Gulf War veterans began in 1992 with the implementation of the Persian Gulf Registry Health Examination Program. In 1993 and 1997, respectively, the Congress passed legislation giving Gulf War veterans special eligibility (priority care) for VA health care and allowing VA expanded authority to treat veterans for health problems that may have resulted from their Gulf War service. In addition to assisting Gulf War veterans in gaining entry into the continuum of VA health care services and providing them with a free physical examination, the Registry database provides a communications link with Gulf War veterans, a mechanism to catalogue prominent symptoms at the time of their examination, and a way to report exposures and diagnoses. In 1995, VA modified the Registry program by implementing the Uniform Case Assessment Protocol, designed in conjunction with DOD and the National Institutes of Health, to help guide physicians in the diagnosis of symptoms reported by veterans who had served in the Gulf War. VA requires medical facilities having a Gulf War program to designate a Registry physician to be responsible for implementing the protocol.

The Registry physician is expected to follow VA's Uniform Case Assessment Protocol, which prescribes a two-phase examination. Phase I requires Registry physicians to (1) obtain a detailed medical history from the veteran, which includes collecting information on exposure to environmental and biochemical hazards; (2) conduct a physical examination; and (3) order basic laboratory tests. Phase II, which is to be undertaken if veterans still have debilitating symptoms that are

undiagnosed after phase I, includes additional laboratory tests, medical consultations, and symptom-specific tests. If followed as written, the protocol gives the Registry physician very little flexibility in deciding what tests should be performed. At the completion of these examinations, veterans are to receive personal counseling about their examination results and need for additional care. In addition, the Registry physician is charged with preparing and signing a follow-up letter explaining the results of the Registry examination. Veterans with continuing medical problems who do not receive a diagnosis after phase II may be sent to one of VA's four Persian Gulf Referral Centers³ for additional testing and evaluation.

Registry physicians are also responsible for clinically managing the treatment of Gulf War veterans and serving as their primary health care provider unless another physician has been assigned. VA's implementing guidance acknowledges that the veterans' Registry physician, or designee, plays a significant role in determining the perceptions veterans have concerning the quality of VA health care services and of their treatment by VA health care providers.

VA's Environmental Agents Service is responsible for overseeing the operation and implementation of the Registry program. The program is currently available to Gulf War veterans at 162 VA medical centers and 50 outpatient clinics nationwide, including Guam, the Philippines, and Puerto Rico.

Estimating the Number of Veterans Suffering From Gulf War-Related Illnesses Remains Problematic

While it is widely accepted that almost 700,000 U.S. service members took part in the Gulf War from August 2, 1990, to July 31, 1991, estimating how many of these veterans suffer from illnesses related to their service in the Gulf region is much more problematic. Although there are certain symptoms that are associated with Gulf War veterans who are ill, there are currently no case definitions⁴ for Gulf War illnesses in use by VA. Veterans may have multiple symptoms or only a few, with no particular pattern of association. Past data collection efforts have been too limited to provide a case definition. In addition, federally supported research projects and Gulf War Registry programs have generally failed to study the conjunction of

³Persian Gulf Referral Centers are located in Birmingham, Ala.; Houston, Tex.; West Los Angeles, Calif.; and Washington, D.C.

⁴"Case definitions" are classifications of symptoms into one or more distinct illnesses.

multiple symptoms in individual veterans.⁵ Further, VA's Under Secretary for Health stated that while the Registry's record of veterans' symptoms, diagnoses, and exposures makes it valuable for health surveillance purposes, the voluntary, self-selected nature of the database means that the exposures, illnesses, and health profiles of those in the Registry cannot be generalized to represent those of all Gulf War veterans. Consequently, only a rough estimate of those potentially suffering from Gulf-related illnesses is possible on the basis of data that report numbers of Gulf War veterans who received services for health complaints of any type.

To obtain a general sense of how many veterans may have suffered adverse health effects as a result of their Gulf War service, we requested information from several VA and DOD health care program databases. We found, however, that while these databases did report on the number of Gulf War veterans receiving certain health care services, they did not indicate whether these services were provided for Gulf War-related conditions. For example, VA reports that over 68,000 Gulf War veterans have participated in its Persian Gulf War Registry program by receiving the Registry examination and being included in the Registry database. However, about 12 percent of these veterans reported no adverse health problems as a result of their Gulf War service. According to the Under Secretary for Health, these veterans wished to participate in the examination only because they were concerned that their future health might be affected as a consequence of their service in the Gulf War.

VA also reports that more than 22,000 Gulf War veterans have been hospitalized, about 221,000 veterans have made outpatient visits to VA facilities, and approximately 83,000 veterans have been counseled in Vet Centers⁶ since the war. Like VA's Registry data, however, there is no indication of how many of these veterans suffer from illnesses that actually resulted from their Gulf War experience.

DOD reports that about 33,000 service members have participated in its Registry examination program but, like VA, does not have information that would definitively link the service members' exposure history to their health problems. Combined, VA and DOD report that over 100,000 Gulf War veterans have requested a Registry examination.

⁵Gulf War Illnesses: Improved Monitoring of Clinical Progress and Reexamination of Research Emphasis Are Needed ([GAO/NSIAD-97-163](#), June 23, 1997), p. 52.

⁶Vet Centers were initially established to assist Vietnam-era veterans in the transition to postwar civilian life. They are now authorized to serve all veterans who may be suffering from readjustment problems that interfere with interpersonal relationships, jobs, educational performance, or their overall ability to cope with daily life.

VA Not Fully Meeting the Health Care Needs of Gulf War Veterans

Although VA has a program in place to help guide physicians in the diagnosis and treatment of Gulf War veterans, this program has not been fully developed and implemented to effectively meet their health care needs. Specifically, VA's diagnostic protocol is not being consistently implemented, and VA referral centers are being underutilized. As a result, some veterans may not be receiving a clearly defined diagnosis for their symptoms. Communication between physicians and veterans has also been less than satisfactory. Mandated personal counseling of veterans often does not occur, and form letters that are sent regarding examination results are not always clear and understandable.

Health care that incorporates diagnosis, treatment, and follow-up is also not well coordinated for Gulf War veterans. Instead, Gulf War veterans are typically referred to one of several primary care teams or physicians who are not always familiar with the symptoms commonly reported by Gulf War veterans. Moreover, VA does not effectively monitor the clinical progress of Gulf War veterans and thus has no way of knowing whether these veterans are getting better as a result of the care provided.

Registry Examination Protocol Inconsistently Implemented

Our reviews of Gulf War veterans' medical records, observation of program operations during site visits, and discussions with program officials, including physicians, showed that VA's Registry examination protocol is not being consistently implemented in the field. For example, our review of veteran's medical records revealed that at two of the six locations we visited the Registry physicians often did not review the results of the examination performed by the physician's assistants or nurse practitioners, as required by the Registry protocol. Moreover, while the protocol mandates that disabled veterans without a clearly defined diagnosis are to receive additional baseline laboratory tests and consultations, these tests and consultations were not typically provided in the facilities we visited.⁷ Our review of 110 veterans' medical records indicated that, in 45 cases, veterans received no, or minimal, symptom-specific testing for unresolved complaints or undiagnosed symptoms.

Furthermore, veterans suffering from undiagnosed illnesses were rarely evaluated in VA's referral centers. Of the approximately 12,500 cases of

⁷We found no evidence that the facilities we visited were applying the criterion that veterans should have a disabling condition as a prerequisite for receiving phase II evaluations.

veterans reported as having health complaints but no medical diagnosis,⁸ only about 500 have been evaluated at a referral center. Of the 110 medical records we reviewed, including those records for veterans with symptoms for whom no diagnosis was provided (24) and those with undiagnosed or unexplained illnesses (30), only 1 record indicated that the veteran was sent to a referral center for evaluation.

While VA central office officials told us that some medical centers are now capable of conducting the more detailed diagnostic tests and analyses typically offered at the referral centers, we found little evidence at the sites we visited that this is taking place. For example, at one full-service medical center we visited, 14 of the 20 cases we reviewed received no diagnosis and 17 received very little, if any, testing. Veterans we spoke with who received care from this facility indicated that they were extremely frustrated and believed that they were not getting adequate testing for their ailments.

Some veterans told us that the examination they received seemed too superficial to fully evaluate the complex symptoms they were experiencing. According to a VA program official, health care providers reported that they spend, on average, about 1 hour to perform each registry examination.⁹ In addition, 24 percent of the records we reviewed (26 of 110) indicated that the diagnoses reached were essentially restatements of the veterans' symptoms. Of these 26, only 11 received symptom-specific treatment or follow-up and referral.

Several of the physicians we interviewed believed they should have the flexibility to use their own clinical judgment in determining which tests are necessary to establish a diagnosis and treatment plan. One VA facility official stated that some physicians do not know that phase II tests are required. One physician stated that a good physician should, in most cases, be able to diagnose a veteran's symptoms without using the more complex battery of tests mandated by the protocol. We were told that some of the phase II symptom-specific tests are invasive procedures that could have serious side effects and, unless the tests are specifically needed, they should not be given routinely just because a veteran has symptoms. Other

⁸Analysis of the Persian Gulf Registry data performed by VA's Office of Public Health and Environmental Hazards shows that the number of veterans who received no medical diagnosis ranges from about 21 to 26 percent of those receiving the examination, depending on when the examination was given.

⁹Information on the time VA facilities report for completing the Registry examination is self-reported and ranges from about 20 minutes to 4 hours. Such wide differences may be explained not only by variations in the actual time spent but also by differences in the facilities' accounting for services provided.

physicians resisted prescribing some phase II tests because of the associated costs. Furthermore, some physicians told us that they believe there are no physical bases for the symptoms Gulf War veterans are experiencing and that these symptoms are often psychologically based and not very serious. According to the Assistant Chief Medical Director responsible for the Registry program, Registry physicians are expected to follow the diagnostic protocol as laid out in program guidance. She added that program guidance is designed to direct physicians' behaviors, not necessarily their attitudes. She told us, however, that the unsympathetic attitudes displayed by some physicians toward Gulf War veterans is inexcusable and cannot be tolerated.

Physicians and veterans in two of the six facilities we visited were often frustrated with the process they were required to follow in obtaining certain tests and consultations. Physicians told us that the lack of existing specialists in these facilities forced them to refer patients to other VA medical facilities for needed services even though this often resulted in increased travel for the veteran, delays in scheduling appointments, and increased waiting times to have consultations and receive test results. Officials at both facilities told us that coordination between VA medical facilities affects not only Gulf War veterans but the entire veteran population.

Personal Counseling Rarely Takes Place

According to VA guidance, counseling veterans about their examination results is one of the key responsibilities of the Registry physician. While VA's guidance provides some criteria on what information should be shared during counseling, the American Medical Association's Physicians' Current Procedural Terminology¹⁰ indicates that counseling discussions with a patient and/or family may concern one or more of the following areas: (1) diagnostic results, impressions, and/or recommended studies; (2) prognosis; (3) risks and benefits of management (treatment) options; (4) instructions for treatment or follow-up; (5) importance of compliance with chosen treatment; (6) risk-factor reduction; and (7) patient and family education.

We found that personal counseling between veterans and their physicians often does not take place. For example, veterans we spoke with indicated that personal counseling is generally not provided on the results of the Registry exam. This is true for veterans who receive a diagnosis as well as

¹⁰The Physicians' Current Procedural Terminology (Chicago, Ill.: American Medical Association, 1998) provides uniform language to describe medical, surgical, and diagnostic services and thereby allows effective communication among physicians, patients, and third parties.

for those who do not. Our review of 110 veterans' medical records revealed that only 39 records, or 35 percent, contained physician documentation of one-to-one counseling about examination results and a discussion of a proposed plan of care. All 39 records were from one facility.

VA medical staff, as well as veterans we talked with, stated that feedback on examination results is typically provided through a form letter. The letter generally states the results of laboratory tests and provides a diagnosis if one was reached. Some form letters sent to veterans at the completion of the examination generated considerable anger among Gulf War veterans. These veterans interpreted the letters to mean that since their test results came back normal, the physicians believed that either there was nothing medically wrong with them or their conditions were not related to their service in the Gulf. Furthermore, at one of the facilities we visited, we were told that counseling letters for more than half of the cases we reviewed were sent to the veterans without incorporating the results of all diagnostic tests.

Treatment Provided to Gulf War Veterans Often Lacks Continuity and Coordination

VA program documentation clearly recognizes the need for continuous and coordinated patient care and the benefits of case management¹¹ as a routine clinical strategy. For example, VA's Gulf War guidance states that Registry physicians play a key role in providing veterans with the Registry examination and necessary treatment, where medically indicated. Reinforcing the need for continuous coordinated care, VA's Under Secretary for Health in an August 21, 1997, information letter on Gulf War Registry health examinations stated that:

"Gulf War veterans with complex medical conditions may require frequent medical follow-up by their primary care teams and various other health care providers. Utilizing case management techniques to coordinate health care services for Gulf War veterans with complex and difficult to manage conditions will improve both treatment effectiveness and patient satisfaction."

In September 1997, VA released an educational video on the use of case management as a tool to improve quality of care in medical centers throughout the VA system. The video cited the Birmingham VA Medical Center's program of case management, which offers continuing and coordinated care for Persian Gulf veterans, as a noteworthy model. In

¹¹Case management is a patient-centered health care process designed to increase the likelihood that patients receive easily accessible, continuous, and high-quality health care through the coordination and integration of services from all health care providers.

response to a congressional mandate, VA has also recently initiated demonstration projects to test health care models that incorporate approaches such as case managers and specialized clinics.¹²

Based on our work, we found that continuous coordinated care was provided at two of the six facilities we visited through the efforts of an individual Registry physician and clinical staff members serving Gulf War veterans. For example, at one facility, veterans have the option of receiving treatment at a Persian Gulf Special Program Clinic. Although it operates only on Tuesdays and Fridays, the clinic allows veterans to receive primary care from medical staff experienced with Gulf War veterans and their concerns. Veterans are still referred to hospital specialists as necessary, but responsibility for tracking patients' overall medical care is assigned to the Persian Gulf clinic's case manager, who is supervised by the Persian Gulf Registry physician. The case manager is a registered nurse who serves as an advocate for veterans and facilitates communications among patients, their families, and the medical staff. The clinic staff also interacts regularly with the Persian Gulf Advisory Board, a local group of Persian Gulf veterans who meet weekly at the VA medical center to discuss specific concerns. Veterans we spoke with were pleased with the clinic and supported its continued operation. They believed that it reflects a VA commitment to take seriously the health complaints of Gulf War veterans. They also believed that the clinic gives veterans access to physicians who understand and care about the special needs of Gulf War veterans and their families. In addition, veterans we talked with who use this facility indicated a high level of satisfaction with the care they received.

At the second facility, the Registry physician served as the veterans' primary care physician. This physician ordered all necessary consults and scheduled follow-up visits for Gulf War patients. He also tracked veterans' visits and documented their environmental exposure histories. Veterans at this facility had a clear point of contact whenever they had questions or concerns about their treatment. Veterans we spoke with told us that they were very satisfied with the treatment they received and were extremely complimentary of the care and concern shown by the Registry physician.

¹²Pursuant to the Veterans' Benefits Act of 1997 (P.L. 105-114, Nov. 21, 1997), the Secretary of Veterans Affairs was required to establish, by no later than July 1, 1998, up to 10 demonstration projects to test new approaches to treating and improving the satisfaction of Gulf War veterans who suffer from undiagnosed and ill-defined conditions. The demonstration projects were to incorporate various approaches including the use of case managers, specialized clinics, and multidisciplinary focused treatment. The law authorizes \$5,000,000 to carry out this activity.

In contrast, at four of the six facilities we visited, we observed that there was very little clinical continuity or coordination among medical professionals during the diagnostic and treatment phases of care provided to Gulf War veterans. Specifically, at these four facilities we found that veterans with symptoms were not always sent for treatment and follow-up care and when they did get treatment they were assigned to primary care teams who treat the general hospital population. Furthermore, some physicians told us that clinical information obtained during the Registry examination is not always forwarded to or used by primary care physicians. As a result, the physicians treating these veterans may not be aware of, or responsive to, their unique experiences and symptoms. Many of the veterans we spoke with who were treated for their symptoms at these four facilities told us that they believed their treatment was ineffective. In fact, several veterans believed their medication made them feel worse and stopped using it. Primary care physicians we spoke with acknowledged that greater continuity between the diagnostic and treatment process would benefit both the physician and the veteran.

In February 1998, VA's Under Secretary for Health said in testimony before the House Committee on Veterans' Affairs that a case management approach intended to improve services to Persian Gulf veterans with complex medical problems had been implemented in 20 of VA's 162 medical centers that have a Persian Gulf Registry Health Examination Program. To determine the specific focus and nature of the case management approaches being utilized, we contacted each of the 20 facilities¹³ identified by VA. Based on our work, we found that provision of continuous coordinated care for Persian Gulf veterans was in place at 8, or 40 percent, of the 20 facilities. Specifically, these eight facilities provided Gulf War veterans with coordinated and continuing clinical care through (1) a singular Registry physician who conducts the examination and provides follow-up treatment, (2) a primary care team dedicated to diagnosing and treating Persian Gulf veterans, or (3) a coordinated effort between the Registry physician who performs the examination and a Persian Gulf primary care team that provides treatment. Although each facility's approach is slightly different, all eight provide links between the diagnostic and treatment phases of care and are focused on the special needs of Gulf War veterans.

The remaining 12 facilities generally do not provide focused, coordinated, or continuing care programs for Gulf War veterans other than the care

¹³One of the facilities identified by VA (Birmingham) was also one of the sites we visited during our review.

available to all veterans. Two of these facilities cited lack of staff as the reason for not attempting or continuing Gulf War dedicated care. For example, one of these two facilities had a dedicated program but recently lost physician staff through budget cuts and has not been able to restart its program.

Increased continuity and coordination between the diagnosis and treatment of Gulf War veterans offers several advantages.

- It validates veteran concerns. By having physicians clearly identified as responsible for the care and treatment of Gulf War veterans, these veterans are more confident that VA takes their complaints seriously.
- It enhances opportunities for veterans to receive follow-up care. After completing the Registry examination, veterans have an immediate point of contact should they have questions about their condition or require follow-up care.
- It allows for increased awareness of VA's referral centers. One of the primary care doctors we spoke with was not aware of the availability of VA referral centers for veterans with undiagnosed conditions or who do not respond to treatment. If designated physicians were responsible for treatment of Gulf War veterans, greater awareness and use of the referral centers would likely take place.
- It allows for a better treatment focus. If designated physicians see the majority of Gulf War veterans, there is an increased likelihood of recognizing symptomatic and diagnostic patterns and developing an effective treatment program. This approach may also lead to greater understanding of the nature and origin of Gulf War illnesses.

Periodic reevaluation and management of patient symptoms, diagnosis, and treatment is part of continuous and coordinated care. This is important for Persian Gulf veterans because of the need to ensure that their diagnosis is correct, assess their progress, check for new symptoms, and determine how they are responding to their treatment plan.

Although VA officials contend that Gulf War veterans are generally being treated appropriately for the symptoms they display, they also recognize the need to evaluate health outcomes and treatment efficacy. In February 5, 1998, testimony before the House Committee on Veterans' Affairs, VA's Under Secretary for Health acknowledged the need to establish mechanisms to evaluate Gulf War veterans' clinical progress and identify effective treatment outcomes. He stated that VA and DOD have jointly asked the National Academy of Sciences' IOM to provide advice and

recommendations on how best to develop and implement a methodology to collect and analyze this type of information. IOM is expected to issue its final report by June 1999.

Gulf War Veterans Often Dissatisfied With VA Health Care

Gulf War veterans are generally dissatisfied with the diagnostic care and treatment they receive from VA for Gulf War-related symptoms. This sentiment was expressed in conversations and communications we had with individuals and groups of Gulf War veterans, the results of our nationwide survey of veterans who received the Persian Gulf Registry health examination in calendar years 1996 and 1997, and findings from VA's satisfaction survey of Gulf War veterans who received outpatient care from fiscal year 1992 through 1997.

Contacts With Gulf War Veterans

In both individual and group discussions and in correspondence, Gulf War veterans indicated that while they greatly appreciated the efforts of some individual doctors, they were often dissatisfied with the overall health care they received from VA. They cited delays in getting the Registry examination; superficial examinations, particularly when they were experiencing complex health problems; and attitudes among health care professionals that implied veterans' physical problems were "all in their heads." Veterans voiced displeasure with the lack of personal counseling and the use of form letters to explain the results of their examinations. They added that these form letters generated considerable anger because they were often interpreted to mean that VA physicians did not believe that veterans were suffering from any physical illness.

Gulf War veterans also indicated that they clearly preferred the use of specific physicians to treat their conditions. Veterans noted that designated physicians tended to be genuinely concerned about their patients and more likely to take their health problems seriously.

GAO's Nationwide Survey of Gulf War Veterans

Recognizing that those who initially communicated with us might be more dissatisfied than the typical Gulf War veteran who receives care, we designed and administered a mail-out questionnaire that we sent to an adjusted random sample of 452 Gulf War veterans.¹⁴ Our sample was selected from 8,106 veterans who received VA's Registry examination

¹⁴Our initial questionnaire mailing was to 477 Gulf War veterans. See app. I for details.

nationwide during calendar years 1996 and 1997.¹⁵ Our survey population was limited to 1996 and 1997 Registry participants because this group received the examination after VA's most recent update to the protocol, which was implemented as of January 1, 1996. The questionnaire collected information on veterans' satisfaction with (1) the Persian Gulf Registry Health Examination, (2) the treatment VA provided, and (3) sources of health care other than VA. Sixty-three percent, or 283, of the 452 veterans surveyed responded. Analyses of the characteristics of nonrespondents showed them to be similar to those of respondents, thus increasing our confidence that our survey results are representative of the views of the sampled population.

Characteristics of Veterans in Our Survey Population

Based on our survey results, we estimate that the median age of veterans in our survey was 33. Seventy-six percent of them were no longer active in the military service, while 12 percent were active in a Reserve Unit, 10 percent were members of the National Guard, and 2 percent were active duty members of the U.S. Armed Services.¹⁶

Because the Persian Gulf Registry examination was first offered in 1992, we asked the veterans to indicate the reasons why they did not receive the examination until 1996 or 1997. One half reported that they did not know that VA offered the examination. Some also reported that they waited to take the examination because they tried to ignore their symptoms at first (40 percent), they believed their problem would go away on its own (33 percent), or their symptoms developed several years after the war was over (19 percent). Fourteen percent were treated by non-VA providers before they requested VA health care.

Almost 60 percent of the veterans rated their current health as either poor or fair, while only about 10 percent rated their health as excellent or very good. In addition, over 80 percent indicated that compared to their health before going to the Gulf, their health now was worse. About three-fourths of the veterans reported experiencing health problems that they believed were caused by their service in the Persian Gulf. Table 1 shows the extent to which various problems were reported by these veterans.

¹⁵This sample allows us to estimate population proportions with sampling errors that do not exceed plus or minus 9 percentage points.

¹⁶Active duty members of the U.S. armed services may request a health examination under VA's Uniform Case Assessment Protocol if they are not comfortable requesting an examination under DOD's Comprehensive Clinical Evaluation Program.

Table 1: Health Problems Reported by Gulf War Veterans Responding to GAO's Survey

Health problem reported	Percentage reporting problem
Muscle and joint pain	73
Memory loss/forgetfulness	69
Behavioral changes	69
Tiredness	68
Sleep disturbances	60
Headaches	54
Skin problems	51
Diarrhea/gastrointestinal disorders	46
Shortness of breath	40

Gulf War Veterans' Satisfaction

Based on our survey results, we estimate that about half of the veterans who received the Registry examination in 1996 and 1997 were dissatisfied with that examination. These veterans often expressed dissatisfaction with specific aspects of VA's examination process. For example, they indicated that VA health providers are generally not very good at communicating with their patients. Specifically, about half of these veterans indicated that they were dissatisfied with their physicians' ability to diagnose their symptoms or explain their diagnosis once one was reached. Moreover, 42 percent were dissatisfied with the explanations provided regarding the need for specific tests, and about 50 percent were not satisfied with the explanations given on the results of these tests. Forty percent were dissatisfied with the thoroughness of the examination.

We estimate that about 45 percent of the veterans who received the examination in 1996 and 1997 and who had health problems they believed were caused by their Gulf War service received treatment from VA. However, about 41 percent of the veterans in our survey who received treatment reported that, overall, they were dissatisfied with the VA treatment services. Forty-eight percent of the veterans who received treatment told us that VA provided little or only some of the treatment they believe they needed. They also indicated that they did not receive treatment they felt was necessary because VA health providers did not believe they needed it (42 percent), treatment was never scheduled (28 percent), or VA providers determined that the veterans' health problems were not related to the Gulf War (22 percent). Even when treatment was provided, veterans were often not satisfied. About 50 percent of respondents who received treatment indicated that they were dissatisfied with their treatment outcomes.

While many veterans we surveyed were dissatisfied with the overall service they received from VA, they were satisfied with certain aspects of the care that VA provided. For example, over half of the veterans we surveyed reported that they were satisfied with the attention (52 percent) and respect (62 percent) paid to them by individual VA physicians.

Almost one half of the veterans in our survey indicated that they sought health care from physicians and medical professionals outside VA for problems they believe were caused by their service in the Persian Gulf. These veterans indicated that they sought care from non-VA health providers because they did not realize that their symptoms were related to their Gulf War service (36 percent), were unaware that they were eligible for the VA services they needed (29 percent), they had to wait too long for a VA appointment (26 percent), and the VA facility was too far away (20 percent).

Sixty-four percent of the respondents also submitted written comments with their surveys. These comments revealed that veterans who receive the examination continue to question VA's willingness to provide them with an adequate diagnosis and treatment for the ailments they are experiencing. For example, some veterans felt that the Registry examination represented little more than a token effort on the part of VA to pacify Gulf War veterans and that the examination did not provide any meaningful answers to their health problems. Other veterans noted that VA in general, and some health care providers in particular, failed to express a genuine concern for the needs of Gulf War veterans. Specifically, these veterans reported that some VA health professionals did not take their problems seriously; questioned their motives in requesting health care services; treated them with disrespect and a lack of sensitivity; and failed to provide adequate explanations of test results, treatment, and follow-up care.

In describing his experience with VA, one Gulf War veteran noted that the doctor who examined him laughed at the problems associated with his medical condition. "He made me feel very embarrassed and humiliated," the veteran stated, adding, "I feel his attitude was anything but professional." The same veteran wrote that he felt the person who examined him had already made up his mind that "there was nothing to Persian Gulf Syndrome and that we (veterans) are either just looking for compensation for nothing, or have just convinced ourselves we're sick when we're not." This veteran also mentioned that he did not believe that the physician took the Registry examination seriously, performed it

thoroughly, or provided adequate treatment for the health problems that were identified.

In describing his frustration with the Registry examination process, another veteran wrote,

“When I arrived I was given a list of questions. I filled out the questionnaire and then was taken back to see the doctor. I gave him the questionnaire; he looked it over and left the room. I was then told by a nurse that I could go. The doctor never asked me one question about my health or my problems. I believe that the doctor could not have cared about my health.”

A third veteran noted that after receiving the examination, he was not notified of its results nor provided with a treatment plan to address his health problems. Another veteran wrote of similar frustrations when trying to receive a diagnosis for his ailments. “[My rash is] easier to live with,” he said, “than trying to get someone [in VA] to find out what [is] wrong.” A fifth veteran indicated that, after receiving an examination, he expected to be given treatment for his continuing health problems but was told by VA personnel that his visit was “just [for the] Registry.”

Other comments we received revealed that veterans are greatly concerned about the impact their Gulf War service has had on the health of their family members. Specific health concerns they noted include miscarriages, Down syndrome, spina bifida, immune system deficiencies, and the premature deaths of young children.

Although the majority of comments we received were critical, several veterans reported satisfaction with the care they received from VA. Some veterans attributed their satisfaction to the efforts and concerns displayed by individual physicians. For example, one veteran stated, “I have been treated very well at the VA center. . . . The doctor I see always answers my questions and always asks what problems I’m having.”

VA’s Gulf War Veteran Satisfaction Survey

VA’s National Customer Feedback Center implemented a survey in 1997 to over 41,000 Gulf War veterans who had received care in a VA outpatient facility during fiscal years 1992 through 1997. Forty percent of the veterans surveyed responded. The survey found that Gulf War era veterans are not satisfied with the continuity and overall coordination of the care they received. The VA survey also showed that Gulf War veterans, as a group, are generally more dissatisfied with VA care than VA’s general outpatient

population that responded to a similar satisfaction survey at an earlier date. For example, while 62 percent of the general patient population responded that the overall quality of care provided by VA was excellent or very good, only 38 percent of Gulf War veterans responded in this way. Twenty-nine percent of the Gulf War veterans rated the quality of VA's care as fair to poor. Furthermore, while 54 percent of the general population reported they would definitely choose to come to the same VA facility again, only 24 percent of Gulf War veterans reported that they would.

IOM Recommends Uniform Care for Gulf War Veterans

In September 1996, VA requested the IOM to conduct an assessment of the adequacy of its Uniform Case Assessment Protocol to address the wide-ranging medical needs of Gulf War veterans and to review the implementation of the protocol. IOM's final report, issued in early 1998, represents another evaluation of VA's Gulf War program and discusses several inconsistencies in the implementation of its protocol. For example, IOM reports that the diagnostic process followed in some VA facilities does not adhere to the written protocol. While stating that it is encouraging that practitioners exercise their clinical judgment to determine what consultations and tests are best for an individual patient, IOM noted that such deviation introduces inconsistency in evaluations across facilities and variations in data recording and reporting. These work against achieving one of the purposes for which the system was developed—to identify previously unrecognized diagnostic entities that could explain the symptoms commonly reported by Gulf War veterans with unexplained illnesses.

The IOM report recognizes that while a great deal of time and effort was expended to develop and implement VA's diagnostic program for Gulf War veterans, new information and experiences are now available that can be used to improve VA's protocol and its implementation. IOM concluded that the goal of implementing a uniform approach to the diagnosis of Gulf War veterans' health problems is admirable and should be encouraged but recommended that a more flexible diagnostic process be adopted and that the protocol's phase I and phase II designations be eliminated. It also recommended that each VA facility adopt and implement a process that would provide Gulf War veterans with an initial evaluation; symptom-specific tests, as needed; and referral for treatment when a diagnosis is reached. If a clear diagnosis cannot be reached, the patient would receive additional evaluation and testing or be sent to a center for special evaluation. Gulf War patients who receive a diagnosis and are referred for treatment would also receive follow-up evaluations under

IOM's proposal. IOM suggested that a defined approach must be established for those who remain undiagnosed or whose major symptoms have not been accounted for, through periodic reevaluation, treatment, or sending the patient to a referral center.

The IOM report also noted that some patients could have diseases that cannot be diagnosed at present because of limitations in scientific understanding and diagnostic testing. IOM's report stated that this group of undiagnosed patients, some of whom are designated as having an "unexplained illness," will contain a diversity of individuals who will require monitoring and periodic reassessment. IOM specifically recommended that VA plan for and include periodic reevaluations of these undiagnosed patients' needs. VA currently has efforts under way to evaluate the IOM recommendations and to develop plans to implement them, where feasible.

Conclusions

Although VA has made progress in some of its VA locations, it has not fully implemented an integrated diagnostic and treatment program to meet the health care needs of Gulf War veterans. While VA has developed a Registry protocol that provides an approach for evaluating and diagnosing Gulf War veterans, that process is not being consistently implemented in the field. As a result, some veterans may not receive a clearly defined diagnosis for their symptoms, and others may be confused by the diagnostic process, thus causing frustration and dissatisfaction.

Furthermore, while VA recognizes that continuous and coordinated patient care will improve both treatment effectiveness and patient satisfaction, many VA facilities have not implemented such an approach for Gulf War veterans. An integrated process should focus services on the needs of Gulf War veterans and should provide a case management approach to the diagnosis, treatment, and periodic reevaluation of their symptoms. Such a focused and integrated process is particularly important for Gulf War veterans because baseline health and postdeployment status information is often not available for this group of veterans. An integrated health care process that provides continuous and coordinated services for Gulf War veterans would not only improve patient satisfaction but also could assist VA health care providers in recognizing symptomatic and diagnostic trends and help identify appropriate and effective treatment options.

Recommendation

We recommend that the Secretary of Veterans Affairs direct the Under Secretary for Health to uniformly implement a health care process for Gulf War veterans that provides for the coordination of

- diagnoses of illnesses,
- treatment of symptoms and illnesses,
- evaluation of treatment effectiveness, and
- periodic reevaluation of those veterans whose illnesses remain undiagnosed.

Agency Comments and Our Evaluation

In commenting on a draft of this report, VA expressed general agreement with our findings and conclusions and concurred with our recommendation that it implement a more uniform, coordinated health care process for Gulf War veterans. VA further detailed its program improvement strategies, which it believes will significantly enhance program responsiveness to the needs of Gulf War veterans and ensure a more integrated treatment process at all organizational levels. VA also mentioned that the timing of our review precluded the observation of resulting improvements from these program improvement strategies. We believe that we have appropriately recognized relevant initiatives in the body of our report and have noted that many of the initiatives are preliminary or in the planning stage.

In two instances, VA took issue with information contained in our draft report. First, VA asserted that our report concludes that “specialized Gulf War clinics are the only effective means to provide coordinated, quality health care.” We disagree with this characterization. Our conclusions focus on the need for an integrated health care process that “provides continuous and coordinated services for Gulf War veterans” and does not identify Gulf War clinics as our preferred model of care. One of the examples of coordinated care cited in our report resulted from the efforts of an individual Registry physician who did not provide care through a specialized Gulf War clinic. As demonstrated by our discussion of the six facilities we visited, we believe that coordinated, quality care can be provided in a variety of settings and through various approaches.

Second, VA said that it believes our report misinterprets the guidance provided for implementation of the phase II Registry examination. VA states that the phase II protocol should be used to “evaluate veterans with debilitating unexplained illnesses, and not for unexplained symptoms, as GAO states” in the background section of the report. We have made

adjustments to the report as appropriate to clarify VA's criteria for initiation of phase II evaluations. The full text of VA's comments is included in appendix II.

Copies of this report are being sent to the Secretary of Veterans Affairs, other congressional committees, and interested parties. We will also make copies available to others upon request.

Please contact me on (202) 512-7101 if you or your staff have any questions or need additional assistance. Major contributors to this report included George Poindexter, Stuart Fleishman, Patricia Jones, Jon Chasson, and Steve Morris.

A handwritten signature in black ink that reads "Stephen P. Backhus". The signature is written in a cursive style with a large initial 'S' and 'B'.

Stephen P. Backhus
Director, Veterans' Affairs and
Military Health Care

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Abbreviations

DOD	Department of Defense
IOM	Institute of Medicine
VA	Department of Veterans Affairs
VHA	Veterans Health Administration
VISN	Veterans Integrated Service Network

Scope and Methodology

Our review consisted primarily of four data collection efforts: (1) reviews of existing databases showing the number of veterans of the Gulf War that VA and DOD report as potentially suffering from related illnesses, (2) work performed at VA's central office and one Veterans Integrated Service Network (VISN) office, (3) case studies at six VA medical facilities including discussions with groups of Gulf War veterans, and (4) implementation of a questionnaire sent to a nationwide sample of veterans who received the Persian Gulf Registry health examination.

Review of Databases

We collected data on the number of veterans who received either some type of VA health care service or who participated in either VA's or DOD's Registry examination program. With the exception of VA's Persian Gulf Registry database, however, we did not address the accuracy or reliability of either agency's databases. Data on VA medical center inpatient and outpatient services were taken from data collected and reported by VA's Gulf War Information System, which, according to VA officials, is the most reliable information available on those services. We also met with officials from VA's Systems Division in Austin, Texas, to discuss the validity of the Persian Gulf Registry Health Examination Program database.

Data Collection at VA's Central Office and VISN 7

Our work in VA's central office in Washington, D.C., and VISN 7 in Atlanta, Georgia, involved primarily the collection of program descriptive material and summary data. We interviewed officials from the Veterans Health Administration (VHA), its Division of Environmental Medicine and Public Health, the Environmental Agents Service, and the VISN 7 office. We collected and reviewed studies, reports, program information, and data from these offices and compared that information with observations made during visits to VA medical facilities and information provided by the Gulf War veterans who communicated with us. We also reviewed testimony, legislation, and reports by others, including the Presidential Advisory Committee on Gulf War Veterans' Illnesses and the National Academy of Science's Institute of Medicine (IOM).

Case Studies

We conducted case study site visits to VA medical facilities in six locations—Albuquerque, New Mexico; Atlanta, Georgia; Birmingham, Alabama; El Paso, Texas; Manchester, New Hampshire; and Washington, D.C. We also visited VA Persian Gulf referral centers in Birmingham, Alabama, and Washington, D.C. We selected these sites judgmentally to include VA facilities that (1) were in different geographical locations,

(2) were varied in size and workload, (3) differed in terms of having an onsite referral center, and (4) implemented their Persian Gulf Registry Health Examination Program using different approaches.

During our site visits, we interviewed Registry program officials on various aspects of program operations, reviewed samples of case files, and discussed specific cases with program physicians. At each VA medical facility we visited, we randomly selected 10 to 40 medical records/case files of program participants who had received a Registry examination after January 1, 1996. We reviewed a total of 110 medical records. While these cases were selected randomly, they are not a representative sample of each facility's total number of Registry program participants.

Through our case study file reviews and discussions with program officials, we obtained detailed information on the types of diagnostic and treatment services provided to Gulf War veterans at each facility. In addition, through our review of medical records, we attempted to identify all efforts to provide continued, coordinated care to veterans who suffer from complex medical problems at the facilities we visited.

We met with groups of Gulf War veterans served by each of the six VA facilities we visited to collect information on their Gulf War experiences, their past and present health status, and the types of health care services they received from VA. We inquired specifically about their satisfaction with VA's Persian Gulf Registry examination and the treatment they received for their symptoms. In addition, we asked them to fill out a questionnaire; however, their responses were not part of our random nationwide survey.

We also contacted the 20 VA medical centers that VA identified as using case management to improve services to Gulf War veterans. One of the 20 centers was also one of our case study locations, and there we discussed program issues with physicians and program personnel. At the 19 sites we did not visit, we talked with physicians and program administrators by telephone to determine the extent to which case management had been implemented and had contributed to continuous and coordinated care for Gulf War veterans.

Discussions With and Survey of Gulf War Veterans

Gulf War veterans with whom we initially spoke often indicated that they believed VA facilities failed to provide them with needed care or that they were dissatisfied with the care provided by VA. Recognizing that those who were most unhappy might be the most likely to contact us or to be critical

when we talked with them, we designed and administered a mail-out questionnaire. We sent the questionnaire to a nationwide random sample of Gulf War veterans who received VA's Registry examination during 1996 and 1997. These 2 years were chosen because VA's most recent update to its protocol, which was intended to make the examination more uniform across all VA facilities, was implemented on January 1, 1996. The questionnaire collected information on the respondents' (1) satisfaction with the Persian Gulf Registry examination, (2) satisfaction with treatment VA provided, and (3) sources of health care outside of VA.

We selected a sample of 477 veterans from a universe of 8,106 veterans who received the Registry examination in 1996 and 1997. To these veterans we mailed (1) a predelivery notification postcard about 2 weeks before questionnaires were mailed and (2) an initial mailing of the questionnaire with a cover letter describing the nature of our survey effort. Of the initial 477 questionnaires mailed, about 100 were returned as nondeliverable. In most cases we were able to mail the questionnaire to a second address by using forwarding addresses provided by the Post Office or addresses provided by a secondary source. Ultimately, 23 veterans in our sample did not receive a questionnaire because of inadequate or incorrect address information. In addition, two questionnaires were returned by family members who reported that the veterans were deceased. Therefore, our adjusted random sample mailing size was 452. Other efforts used to improve the response rate included sending a postcard reminder, 1 week after the initial questionnaire mailing, to all veterans sampled and sending a second questionnaire to all nonrespondents about 5 weeks after the initial mailing. Two hundred eighty-three usable questionnaires were returned. Consequently, the response rate for this survey (defined as the number of usable questionnaires returned divided by the number of questionnaires delivered) was 63 percent. Our survey sample allowed us to estimate population proportions with sampling errors that do not exceed plus or minus 9 percentage points.

Since failure to obtain a response from a sampled veteran could affect the representativeness of the survey data, we conducted analyses to assess the impact of nonresponse. Using information available in VA's Persian Gulf Registry database, we compared respondents and nonrespondents using a variety of demographic and medical characteristics, including whether or not the veteran reported symptoms at the time the examination was administered and self-reported assessments of functional impairments and general health. We found no relationship between any of these characteristics and whether or not the veteran responded to our

questionnaire. On this basis, we believe that respondents did not differ significantly from nonrespondents and, therefore, are representative of the population sampled.

Throughout our review, veterans voluntarily contacted us by telephone, e-mail, and letter to discuss their experiences with illnesses they believe are related to their Gulf War service and the health care they have received from VA. We documented these contacts and used the veterans' comments in our report where appropriate.

Comments From the Department of Veterans Affairs



DEPARTMENT OF VETERANS AFFAIRS
ASSISTANT SECRETARY FOR POLICY AND PLANNING
WASHINGTON DC 20420

JUL 27 1998

Mr. Stephen P. Backhus
Director, Veterans' Affairs and Military
Health Care Issues
U. S. General Accounting Office
441 G Street, NW
Washington, DC 20548

Dear Mr. Backhus:

We have reviewed your draft report, ***VA HEALTH CARE: Better Integration of Services Could Improve Gulf War Veterans' Care*** (GAO/HEHS-98-197) and generally agree with your findings and conclusions. We also concur with GAO's recommendation to implement a more uniform, coordinated health care process for Gulf War veterans. We believe that VHA's program improvement strategies will significantly enhance our responsiveness to the needs of Gulf War veterans in terms of customer satisfaction, and more integrated treatment processes at all organizational levels. Although many of these actions are underway, the timing of GAO's review during the earliest stages of implementation precluded the observation of resulting improvements, many of which are still too immature to be measured.

For example, the Veterans Health Administration (VHA) has already completed a detailed Gulf War veteran satisfaction survey, as well as Gulf War veteran focus groups, to further assess the special needs and concerns of these individuals. Based on the findings, which reflect several of the concerns raised by GAO, VHA decided to conduct the survey annually so that it can more effectively assess patterns of customer feedback over time. We anticipate aggregated data from the next survey to be available by May 1999, and it is our expectation that the impact of new Gulf War veteran initiatives will be reflected in improved levels of satisfaction. The Network-level Service Evaluation and Action Teams (SEAT), established last year to additionally explore specific concerns of Gulf War veterans, also have confirmed issues that GAO raised. The teams will continue oversight of their facilities in Gulf War program activities.

Contrary to GAO's conclusion that specialized Gulf War clinics are the only effective means to provide coordinated, quality health care, VA believes that these veterans can also receive appropriate care in a variety of other settings, such as primary care clinics, multidisciplinary clinics and under a case managed care system. This depends, of course, on whether or not attending clinicians are well

**Appendix II
Comments From the Department of
Veterans Affairs**

2.

Mr. Stephen P. Backhus

informed enough about Gulf War-related health issues to address special needs of these veterans. To assure that all VA practitioners are adequately informed about key issues, VHA has implemented a comprehensive, mandatory continuing medical education program for all physicians. This continuing medical education program synthesizes much information on Gulf War health issues, as well as recent peer-reviewed scientific articles. It is a self-study program that has been very well received by physicians and by groups outside of VA. In fact, the Institute of Medicine recently requested copies of the training package for distribution to all their Committee members who are involved with a variety of Gulf War issues.

VA continues to explore other options in our attempts to identify the most effective treatment modalities and clinical settings. In this regard, we are initiating five clinical demonstration projects for case management and multidisciplinary clinical care for Gulf War veterans. This is in support of a new case management initiative that was introduced last year to improve services to veterans experiencing complex medical problems. The demonstration projects, which are funded for two years, will assess whether health care and patient satisfaction for Gulf War veterans are improved by specialty clinics specifically established for these veterans or by case management approaches.

We are reviewing the clinical protocols for the Registry examination, and will revise them as appropriate, with full consideration of the Institute of Medicine report recommendations. In relation to the protocols, we note that the GAO report misinterprets the guidance provided for implementation of the Phase II Registry examination. The program manual states that the uniform case assessment protocol should be used to evaluate Gulf War veterans with debilitating, unexplained illnesses, and not for unexplained symptoms, as GAO states.

Finally, in our efforts to strengthen national oversight and coordination of Gulf War veterans' health care processes, VHA is establishing a special Gulf War Field Advisory Committee, whose members will include individuals with expertise in a variety of program levels, including those with front line interaction with Gulf War veterans.

Many positive advances have been achieved in addressing the special and highly complex needs of our Gulf War veterans, but our areas of excellence are not always consistently apparent in all facilities. Our own assessments of veteran satisfaction reflect many of the same issues that GAO cites. However, the important program initiatives that VA has already activated, several of which will result in objective improvement measures, will ensure coordination and integration.

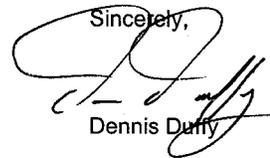
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3.

Mr. Stephen P. Backhus

The enclosure details actions planned and taken to implement GAO's recommendations. We appreciate the opportunity to comment on your draft report.

Sincerely,



Dennis Duffy

Enclosure

**Appendix II
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Action Plan in Response to OIG/GAO/MI Audits/Program Evaluations/Reviews

Name of Report: GAO Draft Report: *VA HEALTH CARE: Better Integration of Services Could Improve Gulf War Veterans' Care*

Report Number: GAO/HEHS-98-197

Date of Report: July 1998

Recommendations/ Actions	Status	Completion Date
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We recommend that the Secretary of Veterans Affairs direct the Under Secretary for Health to uniformly implement a health care process for Gulf War veterans which provides for the coordination of

- diagnoses of illnesses,
- treatment of symptoms and illnesses,
- evaluation of treatment effectiveness, and
- periodic reevaluation of those veterans whose illnesses remain undiagnosed.

Concur

VHA agrees with GAO that a more integrated, coordinated approach in our diagnostic and treatment program is required to meet the health care needs of Gulf War veterans, and we have already taken many proactive steps to assure that program improvements are realized. Because many of our actions were initiated within the past year, it was unfortunately premature for GAO to validate any significant progress as a result of these actions, but we are confident that current and planned efforts described below will result in both increased veteran satisfaction and more consistent systemwide application of clinical programs for Gulf War veterans seeking care in our facilities. Program managers from the Office of Public Health and Environmental Hazards are working in close cooperation with the Chief Network Officer and other key program offices to assure that program initiatives reach fruition. This report will be distributed to all Network Offices, and report findings will also be discussed within the next month during one of the weekly teleconference calls conducted by the Chief Network Officer and attended by top managers from all medical facilities.

Planned

August 1998 and Ongoing

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Could Improve Gulf War Veterans' Care*

In order to acquire more detailed information about veterans' perceptions of their care, we conducted a detailed Persian Gulf veteran customer satisfaction survey during the past fiscal year, the first of what will now become an annual feedback mechanism to measure current levels of customer satisfaction. The Office of Performance and Quality also conducted Gulf War veteran focus groups to further assess the special needs and concerns of these individuals. Results of both the survey and focus groups, which reflected several of the same veteran concerns identified by GAO, were distributed to all of the Network offices for followup review and action.

In Process

May 1999/ Annual

In 1997, under the direction of the Under Secretary for Health, each Network also established a VISN-level Service Evaluation and Action Team (SEAT) to explore specific concerns of Gulf War veterans being treated in their facilities and to identify opportunities for improved responsiveness to veteran needs. Again, the SEATs validated veteran complaints that were also targeted by the customer survey and focus groups. Each Network was provided with the flexibility to develop corrective actions based on individualized local needs. These VISN-level teams will continue to provide liaison oversight to assure that appropriate national directives and educational tools relating to Gulf War issues are fully communicated to involved staff within all of their medical facilities and that facility managers take necessary steps to comply with Gulf War veterans' program guidance, based on the unique characteristics of each facility. When the findings of the next patient satisfaction survey are published (anticipated by May 1999), the SEATs will assess if local initiatives realized their goal to improve veteran satisfaction with health care.

In Process

Ongoing

Because it is VHA's current belief that Gulf War veterans can receive appropriate care in a variety of settings (including primary care clinics, multidisciplinary clinics, Gulf War specialty clinics and under a case managed care system) if the health care providers are adequately informed about their special health concerns, we have implemented a comprehensive, mandatory continuing medical education program for all facility clinicians. Produced by the Office of Public Health and Environmental Hazards in collaboration with the VA Employee Education System, the self-study

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program materials were distributed in March 1998 to VHA physicians. A mechanism to track and test health care providers who completed the self-study material for CME credits is in place. All VA physicians and VA medical libraries have been supplied with the publication, which synthesizes much information on the Gulf War and VA's programs for Gulf War veterans, as well as recent peer-reviewed scientific articles. Multiple teleconference calls have already included discussion of the educational materials, and there has been significant positive feedback from physicians about the usefulness of the package.

In Process

Ongoing

In further pursuit of identifying the most effective treatment modalities and clinical settings, VA is in the process of initiating five clinical demonstration projects (at seven VAMCs) for case management and multidisciplinary specialized Gulf War clinics. Last year, the Under Secretary for Health established a new case management initiative designed to improve services to veterans experiencing complex medical problems, including Gulf War veterans. This initiative has received support from the Presidential Advisory Committee on Gulf War Veterans' Illnesses. In addition, performance measures for the Network Directors have been established to ensure that the appropriate resources are devoted to these efforts at all facilities.

The demonstration projects, which are funded as two-year studies, will support this important effort by using objective outcome measures to assess whether health care and patient satisfaction for Gulf War veterans are improved by multidisciplinary specialized Gulf War clinics or by case management approaches. Funding for three of the projects was awarded this month and the two others are completing review.

In Process

FY 2000 and Ongoing

In order to strengthen national oversight and coordination of the Persian Gulf health care processes, the Office of Public Health and Environmental Hazards is also seeking approval for the establishment of a Persian Gulf Field Advisory Committee, to be comprised of knowledgeable individuals from the national, Network and local levels, including front line providers who directly interact with these veterans. The Advisory Committee will be a central focus for bringing together various levels of program

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activity and for identifying and coordinating opportunities for more effective
integration of health care objectives.

Planned

October 1998 and Ongoing

Related GAO Products

VA Health Care: Preliminary Observations on Medical Care Provided to Persian Gulf Veterans ([GAO/HEHS-98-139R](#), Apr. 20, 1998).

VA Health Care: Persian Gulf Dependents' Medical Exam Program Ineffectively Carried Out ([GAO/HEHS-98-108](#), Mar. 31, 1998).

Gulf War Veterans: Incidence of Tumors Cannot Be Reliably Determined From Available Data ([GAO/NSIAD-98-89](#), Mar. 3, 1998).

Gulf War Illnesses: Federal Research Strategy Needs Reexamination ([GAO/T-NSIAD-98-104](#), Feb. 24, 1998).

Gulf War Illnesses: Research, Clinical Monitoring, and Medical Surveillance ([GAO/T-NSIAD-98-88](#), Feb. 5, 1998).

Gulf War Illnesses: Public and Private Efforts Related to Exposures of U.S. Personnel to Chemical Agents ([GAO/NSIAD-98-27](#), Oct. 15, 1997).

Gulf War Illnesses: Reexamination of Research Emphasis and Improved Monitoring of Clinical Progress Needed ([GAO/T-NSIAD-97-191](#), June 25, 1997).

Gulf War Illnesses: Enhanced Monitoring of Clinical Progress and of Research Priorities Needed ([GAO/T-NSIAD-97-190](#), June 24, 1997).

Gulf War Illnesses: Improved Monitoring of Clinical Progress and Reexamination of Research Emphasis Are Needed ([GAO/NSIAD-97-163](#), June 23, 1997).

VA Health Care: Observations on Medical Care Provided to Persian Gulf Veterans ([GAO/T-HEHS-97-158](#), June 19, 1997).

Defense Health Care: Medical Surveillance Improved Since Gulf War, but Mixed Results in Bosnia ([GAO/NSIAD-97-136](#), May 13, 1997).

Operation Desert Storm: Health Concerns of Selected Indiana Persian Gulf War Veterans ([GAO/HEHS-95-102](#), May 16, 1995).

Operation Desert Storm: Questions Remain on Possible Exposure to Reproductive Toxicants ([GAO/PEMD-94-30](#), Aug. 5, 1994).

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