Measuring the Health of Persian Gulf Veterans: Workshop Summary

Committee on Measuring the Health of Persian Gulf Veterans, Institute of Medicine

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Institute Of Medicine

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This report has been reviewed by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the authors and the IOM in making the published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The contents of the review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their participation in the review of this report: Arthur K. Asbury, M.D., Hospital of the University of Pennsylvania, Philadelphia, Pa.; Margit L. Bleecker, M.D., PhD, Center for Occupational and Environmental Neurology, Baltimore, M.D..; Gerard Burrow, M.D., Yale University School of Medicine; Karl T. Kelsey, M.D., M.P.H., Harvard School of Public Health; David P. Rall, M.D., Ph.D., Washington, D.C.; and Robert B. Wallace, M.D., University of Iowa.

Although the individuals listed above have provided many constructive comments and suggestions, responsibility for the final content of this report rests solely with the authoring committee and the IOM.

Contents

1

Introduction

In December 1997, the Department of Veterans' Affairs (DVA) and the Department of Defense (DoD) asked the Institute of Medicine (IOM) to convene a group of experts to address the issue of measuring the health of Persian Gulf War (PGW) veterans. The purposes of this study are to (1) identify questions regarding the evaluation of the health status of active-duty troops and veterans deployed to the Persian Gulf, (2) identify issues to be addressed in the development of study designs and methods that would be used to answer such questions, and (3) develop a research design(s) and methods that could be used to address such questions. A committee of individuals with expertise in outcomes analysis, study design, research methods, statistics, epidemiology, health status measurement, military databases, clinical medicine, and PGW veterans' health was convened to conduct the study.

The committee organized a workshop on May 7, 1998, the purpose of which was to provide its members with background information on the health concerns of PGW veterans and an overview of research on this topic as a starting point for committee deliberations. This report of the presentations and discussion at that invitational workshop is being prepared in response to a request from the study sponsors, DVA and DoD. The report is strictly a summary of the workshop. It does not contain committee findings or recommendations because the committee has not yet conducted a systematic evaluation of the information presented by the speakers, nor has it reviewed the additional research conducted but not presented during the workshop.

The topics covered included descriptive statistics of PGW veterans' symptoms, complaints, and diagnoses; population and sample survey research; health databases within DVA and DoD; PGW veteran research efforts in the United Kingdom; and reflections on the health of patients in the DoD Specialized Care Program. A period was also devoted to open testimony, and DoD contractors presented a concluding discussion of a draft research protocol. The agenda and participant list appear in Appendix A.

2

Background

On August 2, 1990, Iraq invaded the independent nation of Kuwait. Within 5 days the United States had begun to deploy troops to the Persian Gulf in Operation Desert Shield. Intense air attacks against the Iraqi forces began on January 16, 1991 (Operation Desert Storm), and a ground attack was launched on February 24, 1991. Within 4 days Iraqi resistance crumbled. Almost 700,000 U.S. troops participated in the Persian Gulf War. Following the fighting the number of U.S. troops in the area began to decline rapidly. By June 1991 fewer than 50,000 U.S. troops remained in the Persian Gulf region.

The demographic characteristics of the Persian Gulf troops differed from those involved in previous military engagements. Overall, they were older, a large proportion (about 17 percent) were from National Guard and Reserve units, and almost 7 percent of the total forces were women.

U.S. casualties during the Persian Gulf War were low. There were 148 combat-related deaths, with an additional 145 deaths due to disease or accidents. Despite the low numbers of U.S. fatalities and injuries, the deployed personnel were exposed to a number of stressors. The rapid mobilization for military service led to the sudden disruption of the lives of large numbers of people. The involvement of large numbers of reservists and National Guard personnel created particular concern because, in addition to their rapid mobilization and deployment, they would be returning directly to civilian life at the conclusion of the war.

U.S. troops were exposed to oil smoke, diesel and jet fuel, solvents and other petrochemicals, chemical agent resistant coating paint, depleted uranium, sand, endemic infections such as leishmaniasis, extreme heat, and primitive living conditions. In addition, some soldiers were given vaccines against anthrax and botulinum toxins, and some soldiers ingested pyridostigmine bromide pills as protection against chemical warfare agents.

Other conditions affecting the troops were the unfamiliar character of the region, the requirement that U.S. military personnel have virtually no interaction with the indigenous populations, the waiting for the fighting to begin, the fear that chemical warfare agents would be used by the Iraqis, and the immense destruction visited on the nations of Kuwait and Iraq.

After the war most veterans returned home and resumed their normal activities. Within a relatively short time, however, some active-duty military personnel and veterans began to report various health problems that they believed were connected to their service in the Persian Gulf. Symptoms commonly described included fatigue, memory loss, severe headaches, muscle and joint pain, and rashes (Iowa Persian Gulf Study Group, 1997).

In 1992, DVA developed and implemented the Persian Gulf Registry. Its original purposes were to facilitate the entry of returning veterans into the DVA health care system, to create a registry containing medical and other data on PGW veterans that would assist in addressing questions about

possible future effects of exposure to air pollutants and other environmental agents, and to serve as the basis for future medical surveillance. Exposures, particularly those associated with the oil well fires, were included as part of the history taking. As time passed it became apparent that a number of exposure issues and a host of symptoms needed further investigation.

As concern over the health problems of those deployed to the Persian Gulf escalated, DoD also decided to develop and implement a Persian Gulf clinical program for PGW veterans. DoD and DVA met and used experts to develop clinical protocols. By 1994 both had implemented similar and parallel clinical evaluation programs. The DVA clinical program is called the Persian Gulf Registry and Uniform Case Assessment Protocol (PGR/UCAP), while the DoD program is called the Comprehensive Clinical Evaluation Program (CCEP). By early 1997 almost 100,000 veterans had been examined through either the DVA (about 67,000) or the DoD (about 33,000) Persian Gulf Registry program.

Concern about the health of PGW veterans has led to a number of investigations and reports, many of which contain recommendations for research or for improving the diagnostic programs of DVA and DoD. Several population-based studies regarding the health of PGW veterans have been conducted. Most of these focus on specific components of health status or outcome, for example, mortality and hospitalizations. A major study of self-reported health complaints was jointly undertaken by the Centers for Disease Control and Prevention and the University of Iowa, but it was limited to Iowa residents. Another effort aimed at determining the health outcomes of troops deployed to the Persian Gulf compared to those of troops not deployed to the Gulf is the DVA National Health Survey of Persian Gulf Veterans and Their Family Members, the results of which are not yet available.

Despite these efforts to study the health of PGW veterans, many individuals in the U.S. Congress, in the federal government, and among the public believe that no study has yet been designed that adequately measures the health of those deployed to the Persian Gulf.

A recently released General Accounting Office (GAO) report concluded that “although efforts have been made to diagnose veterans' problems and care has been provided to many eligible veterans, neither DoD nor VA [DVA] has systematically attempted to determine whether ill PGW veterans are any better or worse today than when they were first examined” (GAO, 1997). The report also concluded that DoD and DVA have no systematic approach to monitoring the quality, appropriateness, or effectiveness of care provided to PGW veterans after their initial examination and that these agencies need to develop a plan to collect longitudinal information on the health outcomes and treatment effectiveness of PGW veterans.

After reviewing the GAO findings, the U.S. House of Representatives Appropriations Committee issued Report 105–175 which states that DoD and DVA should develop and implement a plan to provide (1) data on the effectiveness of the treatments received by these veterans and (2) longitudinal information on the health of veterans who reported diagnosed and undiagnosed illnesses after the war.

In response to these recommendations, the DVA and the DoD asked the IOM to conduct a study aimed at developing a research design to measure the health of Persian Gulf veterans. The first meeting of the Committee on Measuring the Health of Persian Gulf Veterans included a workshop designed to collect information regarding the health problems of those deployed to the Persian Gulf War and some of the efforts that have been made to study those problems. The following sections of this report provide a summary of that workshop.

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Workshop Presentations

Two speakers provided descriptive information regarding the diagnostic programs developed by DVA and DoD for evaluating the health problems of PGW veterans. Five speakers presented population-based and sample survey research studies of PGW veterans' health including self-reported illness and health status, the National Health Survey of Persian Gulf Veterans and Their Families, mortality, postwar hospitalizations, and patient satisfaction with DVA care. The information presented by speakers is described, as is a discussion of the strengths and weaknesses of the research studies. A systematic evaluation of the quality of those studies has not been conducted by this committee, and therefore, this report should not be viewed as including any committee conclusions or recommendations. It is a *summary* of the workshop, not an evaluation of the information presented at the workshop.

During the workshop DVA and DoD staff described the databases available within their departments for examination of various aspects of the health of PGW veterans, a presentation on reflections on the health of the patients in DoD Specialized Care Program was made, and a period of open testimony was held. The workshop concluded with a discussion of a protocol developed by DoD to measure the health of those who had participated in CCEP.

DVA AND DOD DIAGNOSTIC PROGRAMS FOR EVALUATING HEALTH PROBLEMS OF PERSIAN GULF VETERANS.

DVA and DoD have implemented similar clinical diagnostic programs for the evaluation of health complaints of PGW veterans: PGR/UCAP and CCEP, respectively. Both systems have a Phase I examination that consists of a medical history, a physical examination, and a few basic laboratory tests. If at the conclusion of the Phase I examination a diagnosis that explains the patient's major health complaints has not been made, the individual is referred to Phase II. During Phase II individuals receive supplemental laboratory tests and consultation examinations based on the symptoms that they exhibit. If at the conclusion of this phase a diagnosis still has not been made, a patient in the DVA system may be referred to one of four Persian Gulf Referral Centers for more extensive testing. In DoD, a small number (about 80) of individuals have been referred to the Specialized Care Program at Walter Reed Army Medical Center for an intensive 3-week evaluation and treatment program.

For both systems, data obtained at the examination facility are recorded on the Persian Gulf Registry Code Sheet and sent to a central processing source for aggregation. The data collected include basic demographic information (e.g., age, sex, marital status, and race/ethnicity), military

service information (e.g., branch of service, rank, and unit), self-reported exposure information, up to 10 symptoms, and up to 10 diagnoses. Although these data are useful from a clinical perspective they are limited for use as research data because participants are self-selected, protocols for diagnosis have not been standardized, and procedures for recording information on the code sheet are not consistent across facilities. In addition, in April 1996 a revised code sheet was implemented but it does not allow the aggregation of obtained data pre-and postimplementation.

DESCRIPTIVE STATISTICS

Of the nearly 697,000 individuals deployed to the Persian Gulf War, approximately 535,000 are now eligible for care through DVA. The remainder may still receive care through the DoD. Of those veterans eligible for DVA care, about 230,000 have received DVA outpatient care and more than 33,000 veterans have been hospitalized in DVA medical centers.

Table 1 displays some of the basic demographic and military service characteristics of 83,197 individuals who served in the Persian Gulf War and who have participated in either the DVA or the DoD special diagnostic program.

DVA Persian Gulf Registry and Uniform Case Assessment Protocol

Dr. Frances Murphy presented information about participants in the DVA PGR/UCAP. According to Dr. Murphy, the code sheet revision implemented in 1996 makes it impossible to aggregate complaint, symptom, and diagnostic data for the total population of veterans whose data are recorded in DVA PGR/UCAP. The revision does, however, allow the capture of more information than could be captured on the original code sheet. There is a greatly expanded self-report exposure history questionnaire. In addition, although the original recording from allowed up to 3 symptoms and up to 3 diagnoses to be listed, the revised form allows expanded recording of up to 10 symptoms and up to 10 diagnoses. Table 2 presents information indicating that 98 percent of veterans have 10 or fewer complaints. Looking at the number of veterans with 3 or fewer complaints encompasses only 55.4 percent of the population seen. By placing the cutoff at 3 complaints, Dr. Murphy hypothesized that DVA may have missed as many as 50 percent of the symptoms that the first 52,835 individuals through the registry would have reported.

TABLE 1 Demographic and Military Service Characteristics of the Conflict Veterans Participating in the DoD CCEP, the DVA PGR/UCAP, and both CCEP and PGR/UCAP

	Percent			
Demographic or Military Service Characteristic	All PGW Veterans[a] (*N* = 696,530)	CCEP[b] (*N* = 27,747)	PGR/UCAP[c] (*N* = 57,253)	CCEP and PGR[d] (*N* = 83,197)
Age Group (yr) (1991)				
Less than 25	42.0%	24.2%	37.0%	33.1%
25–34	39.7	48.9	34.6	39.4
35–44	15.5	23.7	21.5	21.9
45–54	2.6	2.9	6.2	5.0
55–64	0.2	0.2	0.7	0.6
Over 65	0.0	0.0	0.0	0.0

Demographic or Military Service Characteristic	Percent			
	All PGW Veterans[a] (*N* = 696,530)	CCEP[b] (*N* = 27,747)	PGR/UCAP[c] (*N* = 57,253)	CCEP and PGR[d] (*N* = 83,197)
Sex[e]				
Male	89.1	89.7	89.8	89.9
Female	6.9	10.3	10.2	10.1
Unknown	4.0	0.0	0.0	0.0
Race				
White	65.3%	55.4%	64.5%	61.5%
Black	21.8	32.9	23.6	26.6
Hispanic	4.8	5.1	5.5	5.4
American Indian	0.6	0.6	0.8	0.7
Asian	2.2	1.5	1.1	1.2
Other	1.3	2.3	1.3	1.6
Unknown	4.1	2.3	3.2	3.0
Marital Status				
Married	48.0	66.4	49.8	54.9
Single	45.1	26.8	42.6	37.7
No longer married	2.8	4.5	4.4	4.4
Unknown	4.1	2.3	3.2	2.9
Highest Level of Education				
Elementary school	0.5	0.3	1.4	1.0
High school	1.8	0.8	1.3	1.1
High school diploma	73.7	73.7	74.9	74.7
Some college	2.5	5.0	2.8	3.5
Bachelor's degree	10.0	8.3	10.2	9.5
Master's degree	2.2	2.2	1.4	1.6
Post-master's degree	4.1	6.1	4.0	4.7
Other/unknown	5.2	3.5	4.1	3.9
Branch				
Army	50.4	84.5	73.3	76.8
Air Force	11.9	6.8	6.4	6.5
Marine Corps	14.9	5.0	13.0	10.5
Navy	22.7	3.7	7.1	6.0
Coast Guard	0.1	0.1	0.2	0.2
Pay Grade				
Enlisted	89.3	89.9	93.2	92.2
Officer	9.5	7.7	5.6	6.3
Warrant	1.2	2.4	1.1	1.5
Military Component				
Active duty	83.9	91.1	60.7	70.9
Reserve and Guard	16.1	8.9	39.3	29.1

[a]PGW veterans consisted of all military personnel deployed to the Persian Gulf between August 1, 1990, and July 31, 1991.
[b]DoD CCEP participants, inception to December 10, 1997.
[c]DVA PGR/UCAP participants, inception to November 27, 1997.
[d]Unique veterans from both registries (1,803 individuals included in both registries).
[e]If sex was unknown in the Defense Manpower Data Center roster, sex as recorded in the registry was used to tabulate the data.

TABLE 2 Frequency Distribution of 8,999 PGW Veterans' Complaints

Number of Complaints per Veteran	Number of Veterans	Percent	Cumulative
0	78	0.8	
1	1,512	16.8	17.6
2	1,703	18.9	36.5
3	1,724	19.2	55.7
4	1,247	13.9	69.6
5	921	10.2	79.8
6	604	6.7	86.5
7	380	4.2	90.7
8	244	2.7	93.4
9	167	1.9	95.3
10	275	3.1	98.4
>10	144	1.6	100.0
TOTAL	**8,999**	**100.0**	

Data are as of October 1997, and were prepared by the DVA Office of Public Health and Environmental Hazards.

Table 3 displays the most frequent complaints of veterans whose data are recorded in DVA PGR/UCAP separately, with data presented for those recorded on the original and the revised code sheets: (1) the first 52,835 veterans for whom the original code sheet was used and (2) the most recent 10,075 veterans for whom the revised code sheet was used.

TABLE 3 Most Frequent Complaints Among Veterans in DVA PGR

	Original Code Sheet[a]		Revised Code Sheet[b]	
Complaint	Number (*N* = 52,835)	Percent	Number (*N* = 10,075)	Percent
Fatigue	10,847	20.5	2,428	24.1
Skin rash	9,719	18.4	2,333	23.2
Headache	9,525	18.0	2,577	25.6
Muscle, joint pain	8,871	16.8	2,258	22.4
Loss of memory and other general symptoms	7,406	14.0	2,906	28.8
Shortness of breath	4,190	7.9	1,075	10.7
Sleep disturbances	3,111	5.9	1,244	12.4
Diarrhea and other gastrointestinal symptoms	2,416	4.6	1,130	11.2
Other symptoms (involving skin and integumentary tissue)	1,916	3.6	374	3.7
Chest pain	1,847	3.5	480	4.8
Choking sensation (mouth breathing, etc.)	NA	NA	563	5.6
Abdominal pain	NA	NA	453	4.5
Cough	NA	NA	339	3.4
No complaint	6,496	12.3	1,032	10.2

[a] Data are as of November 1996, were prepared by the DVA Environmental Epidemiology Service, and are based on data in the original code sheet.
[b] Data are as of October 1997, were prepared by the DVA Office of Public Health and Environmental Hazards, and are based on data in the revised code sheet implemented in 1996.
[c] NA, not available.

Table 4 presents information on the distribution of diagnoses for those who have been examined as part of the DVA PGR/UCAP. For some diagnoses the frequencies are different across the two groups. DVA hypothesizes that one factor for these differences may be code sheet revision.

TABLE 4 Distribution of Diagnoses for Veterans in the PGR/UCAP

	Original Code Sheet[a]		Revised Code Sheet[b]	
Diagnosis	Number (*N* = 52,835)	Percent	Number (*N* = 10,075)	Percent
Musculoskeletal and connective tissue	13,299	25.2	3,606	35.8
Mental disorders	7,995	15.1	3,308	32.8
Respiratory system	7,540	14.3	1,839	18.3
Skin and subcutaneous tissue	7,144	13.5	1,881	18.7
Digestive system	6,028	11.4	1,649	16.4
Nervous system	4,398	8.3	1,689	16.8
Circulatory system	3,747	7.1	1,007	10.0
Infectious diseases	3,715	7.0	882	8.8
Injury and poisoning	2,485	4.7	1,100	10.9
Genitourinary system	1,774	3.4	547	5.4
Neoplasm	232	0.4	69	0.7
No medical diagnosis	13,998	26.5	2,114	21.0

[a] Data are as of November 1996, were prepared by the DVA Environmental Epidemiology Service using the original code sheet, and are published in a report by Kang et al. (1997).
[b] Data are as of October 1997, were prepared by the DVA Office of Public Health and Environmental Hazards using the revised code sheet, and were distributed at the May 7, 1998, IOM workshop on Measuring the Health of PGW Veterans.

DVA also collected information on self-reported health status and functional impairment of the 10,075 veterans whose data are in the revised registry. These data are displayed in Table 5. A survey questionnaire was mailed to the first 52,835 veterans whose data are in the original registry in an attempt to capture information on health status. The response rate was about 50 percent with higher response rates from members of the Reserves and the National Guard, from individuals who were white, and from those who were older.

TABLE 5 Self-Reported Health Status and Functional Impairment of 10,075 Veterans in the Revised PGR/UCAP

Status	Percent
Health	
Very good/good	33.9
All right	40.7
Poor/very poor	25.4
Impairments	
None	25.6
Slight	36.5
Moderate	30.5
Severe	7.4
Smoking (currently)	
Yes	32.3
No	67.7

NOTE: Data are as of October 1997, and were prepared by the DVA Office of Public Health and Environmental Hazards.

Of those responding, 45 percent reported that their health status had not changed since their original examination, 19 percent reported they were better than they had been previously, and 36 percent reported that their health status had worsened. Unfortunately, data regarding respondents' baseline health status and functional impairment were not available.

Information is collected through the registry at the time of initial evaluation only. No follow-up information regarding treatment or health status is collected on a regular basis.

DoD Comprehensive Clinical Evaluation Program

COL Bruce Jones presented data on PGW veterans seen in the diagnostic program implemented by DoD. These data are compiled and presented separately from data regarding DVA participants because of differences in reporting, as discussed earlier. Table 6 provides information on the most common complaints of those seen in the CCEP. The data are divided into two groups: data collected prior to the implementation of the revised code sheet and data collected following implementation of the revised code sheet.

TABLE 6 Most Frequent Complaints Among Veterans in DoD CCEP

	Original Code Sheet[a]		Revised Code Sheet[b]	
Symptom	Number (*N* = 18,495)	Percent	Number (*N* = 10,242)	Percent
Joint pain	8,512	46.7	5,888	57.5
Fatigue	8,059	44.2	5,017	49.0
Headache	6,796	37.3	3,904	38.1
Memory loss	6,046	33.2	4,296	41.9
Sleep disturbance	5,962	32.7	4,247	42.5
Rash	5,059	27.8	2,680	26.2
Difficulty concentrating	4,866	26.7	3,537	34.5
Depressed mood	4,023	22.1	2,080	20.3
Muscle pain	3,918	21.5	3,103	30.3
Diarrhea	3,224	17.7	1,523	14.9
Shortness of breath	3,168	17.4	2,517	24.6
Abdominal pain	2,932	16.1	1,587	15.5
Hair loss	2,182	12.0	2,156	21.1
Bleeding gums	1,526	8.4	1,265	12.4
Weight loss	1,219	6.7	1,083	10.6

[a] Data were collected for the first 18,495 participants in the CCEP from inception until April 1996, by using the original code sheet.
[b] Data were collected for the 10,242 participants in the CCEP from April 1996 through March 1998, by using the revised code sheet.

Table 7 presents information on the distribution of diagnoses for those seen in the CCEP. The data are, again, presented in two groups because of the code sheet revision.

Col. Jones emphasized that it is important when examining data from either the CCEP or PGR/UCAP to remember that these are not research-quality data because populations are self-selected, protocols for diagnosis are not standardized, and procedures for recording information on the code sheet are not consistent across facilities.

TABLE 7 Distribution of Diagnoses for Participants in CCEP

	Original Code Sheet[a]		Revised Code Sheet[b]	
Diagnosis	Number (*N* = 18,495)	Percent	Number (*N* = 10,242)	Percent
Musculoskeletal	3,419	18.8	2,140	22.1
Psychoses and mental disorders	3,385	18.6	1,645	17.0
Signs, symptoms, and ill-defined conditions	3,236	17.8	1,721	17.7
Healthy	1,712	9.4	583	6.0
Respiratory system	1,226	6.7	597	6.2
Digestive system	1,141	6.3	626	6.5
Skin and subcutaneous tissue	1,152	6.3	564	5.8
Nervous system and sensory organs	1,047	5.8	512	5.3
Infectious diseases	457	2.5	268	2.8
Circulatory system	383	2.1	302	3.1
Endocrine/nutritional/metabolic diseases	366	2.0	248	2.6
Genitourinary system	226	1.2	140	1.4
Injury and poisoning	140	0.8	117	1.2
Neoplasms	153	0.8	102	1.1
Blood and blood-forming organs	105	0.6	67	0.7

[a] Data were collected for the first 18,495 participants in the CCEP from inception until April 1996, by using the original code sheet.
[b] Data collected for the 10,242 participants in the CCEP from April 1996 through March 1998, by using the revised code sheet.

Several research efforts have been undertaken, however, to measure the health of PGW veterans. The following sections present information on population-based studies and databases available for the conduct of such studies.

POPULATION AND SURVEY SAMPLE RESEARCH

Published studies designed to measure the health of PGW veterans include information about self-reported illness and health status, mortality, and postwar hospitalizations. During the committee-organized workshop Measuring the Health of Persian Gulf Veterans, held on May 7, 1998, presenters described major studies that had been completed or that are in progress.

Two major efforts have been mounted to measure and compare the health status of PGW veterans and nondeployed veterans. The first of these efforts was conducted jointly by the Centers for Disease Control and Prevention and the University of Iowa College of Medicine and is referred to as the Iowa Study Group. The second study is under way. It was designed and implemented by the Environmental Epidemiology Service of DVA and is called the National Health Survey of Persian Gulf Veterans and Their Families.

Self-Reported Illness and Health Status Among Gulf War Veterans

The results of a study conducted by the Iowa Study Group, *Self-Reported Illness and Health Status Among Gulf War Veterans,* were published in the *Journal of the American Medical Association* and were presented at the workshop by one of the coauthors, Dr. David A. Schwartz (Iowa Persian Gulf Study Group, 1997). The purposes of that study were to (1) assess the prevalence of self-reported health conditions among PGW veterans from Iowa, (2) compare those rates with the prevalence of these conditions among military personnel not deployed to the Persian Gulf, and (3) explore the relationship between self-reported health conditions and type of military service (regular military versus National Guard or Reserve).

Two criteria were used to determine eligibility for inclusion in the sample: (1) Iowa was listed as the individual's home state on the military record and (2) military service had to occur from August 2, 1990, through July 31, 1991. Study participants were divided into four domains: PGW regular military, PGW National Guard or Reserve, non-PGW regular military, and non-PGW National Guard or Reserve. The sampling approach was a randomized, stratified sample with proportional allocation. Within each of the four domains the sample was stratified according to age, sex, race, rank, and branch of military service. The goal was to interview 750 subjects from each domain.

Eventually, 2,400 eligible PGW veterans were identified, as were about 2,400 eligible non-PGW veterans. Seventy-eight percent of the eligible PGW veterans and 73 percent of the non-PGW veterans agreed to participate in the study.

The study questionnaire consisted of a series of validated questions and questionnaires that were drawn from other studies plus additional items developed as needed. The questionnaires included selected items from the National Health Interview Survey, the Behavioral Risk Factor Surveillance Survey, the Health Status of Vietnam Veterans Telephone Survey, the National Medical Expenditures Survey, the Primary Care Evaluation of Mental Disorders, the Brief Symptom Inventory, the CAGE questionnaire, the Post Traumatic Stress Disorder (PTSD) Checklist-Military, the Centers for Disease Control and Prevention chronic fatigue syndrome questionnaire, the Chalder Fatigue Scale, the American Thoracic Society questionnaire, and the Sickness Impact Profile. Additional questions developed by the investigators assessed fibromyalgia, sexual functioning, and military exposures. The Medical Outcomes Study Short Form (SF 36) was used to assess health-related quality of life.

The study was conducted in several stages. First, each individual received an introductory letter. Within a week of receipt of that letter, they received their first telephone call, which consisted of a 10-minute interview in which basic demographic data were collected and a time for the main telephone interview was scheduled. The main telephone interview collected the health and exposure information and took about 60 minutes (range, 28 to 185 minutes). These interviews were conducted between September 1995 and May 1996.

Prior to analyzing the responses, the researchers identified specific health outcomes of particular interest for investigation. Primary concerns included depression, PTSD, chronic fatigue, airway disease, and cognitive dysfunction. Additional health concerns included general health, functional health status, reproductive health, cancer, fibromyalgia, multiple chemical sensitivity, substance abuse, anxiety, and injuries. Researchers anticipated these to be the health outcomes most likely to represent problems in the PGW veteran population.

The overall response rate was 76 percent. Those participating were from units that, during the Persian Gulf War, were spread throughout the Persian Gulf War theater. Table 8 presents a comparison of the estimated prevalence of symptoms in the PGW and non-PGW veterans surveyed. Compared to non-PGW veterans, PGW veterans had significantly higher prevalences of symptoms of depression, PTSD, chronic fatigue, cognitive dysfunction, bronchitis, and asthma. Among the PGW veterans, minimal differences were observed between National Guard or Reserve members and regular military troops.

TABLE 8 Estimated Prevalence of Self-Reported Symptoms of Specific Conditions

	Estimated Prevalence (percent)		
Symptoms	PGW Veterans	Non-PGW Veterans *(N* = 1,799) Percent	Prevalence Difference (95% CI)
Cognitive dysfunction	18.7	7.6	10.9 (9.0–12.7)
Fibromyalgia	19.2	9.6	9.3 (7.3–11.2)
Depression	17.0	10.9	6.0 (4.0–7.9)
Anxiety	2.8	1.3	2.7 (1.8–3.7)
Alcohol abuse	17.4	12.6	2.4 (0.4–4.5)
Asthma	7.2	4.1	2.3(0.7–3.9)
Bronchitis	3.7	2.7	2.3 (1.1–3.4)
Chronic fatigue	1.3	0.3	1.4 (0.9–2.0)
PTSD	1.9	0.8	0.9 (0.3–1.5)

NOTE: Data were controlled for age, sex, race, branch of military, and rank.

For the major medical and psychiatric conditions, the largest difference between PGW veterans and non-PGW veterans was for symptoms of cognitive dysfunction. With the exception of symptoms of chronic fatigue and alcohol abuse, even greater differences were observed between PGW veterans who served in the National Guard or Reserves and non-PGW veterans who served in the National Guard or Reserves.

Overall, 52 percent of the population studied had none of the conditions measured, 21 percent had one of the primary conditions, and 15 percent had two or more of the primary conditions, whereas 24 percent had one of any of the conditions and 24 percent had two or more of any of the conditions. Assessment of functional activity by using the SF 36 found that the PGW veterans had a depressed level of functioning for cognitive, physical, and work activities compared to the non-PGW veterans.

The conclusions from this study were as follows: (1) PGW veterans report specific medical and psychiatric conditions at higher rates than their military peers who were not deployed to the Persian Gulf; (2) further clinical evaluation is needed to investigate the relationship between these self-reported conditions and clinical illness; (3) the conditions identified appear to have had a measurable impact on the functional activity and the daily lives of the PGW veterans; and (4) among PGW veterans, minimal differences were observed between the National Guard or Reserve members and the regular military troops.

Dr. Schwartz believes the strengths of this study include that it was hypothesis driven, it used random stratified sampling with a control study group, it had a high rate of participation, and it used standardized, validated survey instruments, although these instruments were revised in some cases. The weakness is that the sample was drawn from the population in a single state, Iowa, and therefore, the results are not generalizable to the entire population of PGW veterans. In particular, there were very few women members and minority groups in the study sample.

The Iowa Study Group is conducting a range of analyses using data from the study, including an attempt to determine whether any unique syndrome exists within this population. The analysis of whether a unique syndrome exists is being led by Dr. Bradley N. Doebbeling, a member of the Iowa Study Group. On the basis of his analysis, Dr. Doebbeling has found that reported symptoms appear to fall into one of three factor scales or groups for both the PGW veterans and the non-PGW veterans. These are (1) somatic (joint stiffness, muscle aches, weakness, numbness or tingling, headaches, nausea, extreme fatigue, frequent dyspnea on exertion, dizziness tremors); and (2) distress (nervous, worrying, feeling depressed, feeling down, difficulty concentrating, anhedonia, restless, irritable, easily startled, confused); or (3) panic (heart racing/pounding, anxiety attack, attack dyspnea, attack

sweats, attack chest pain). These same clusterings of factors were found for both the PGW veterans and a comparable group of military personnel that was not deployed to the Persian Gulf, suggesting that these factors were not unique to those who were deployed to the Persian Gulf War.

Other analyses include examinations of health services utilization, multiple chemical sensitivity, injury, PTSD, women's health issues, health-related quality of life, and birth defects.

Dr. Schwartz concluded by emphasizing that two structural components of the study were especially important: the Scientific Advisory Committee and the Public Advisory Committee. The Scientific Advisory Committee was composed of six senior scientists and provided advice and consultation including review and critique of the study design, survey instruments, outcomes measures, analytic methods, reporting strategies, and future research initiatives. The Public Advisory Committee was composed of 19 members who ensured input from veterans' organizations and assisted with public support of the project.

The National Survey of Persian Gulf Veterans and Their Families

In April 1994, the Technology Assessment Workshop Panel of the National Institutes of Health recommended that an estimate of the prevalence of symptoms, more accurate than that provided by DVA registry, be developed for PGW veterans and their family members. In November 1994, PL 103–446 directed the Secretary of DVA to conduct a health survey of PGW veterans and to evaluate the health status of the spouses and children of those veterans. In response, DVA began developing its National Survey. Dr. Han Kang provided an overview of this National Survey.

The stated purposes of the survey are to (1) estimate and compare the prevalence of various symptoms and other health outcomes among PGW veterans and non-PGW veterans; (2) estimate and compare the prevalence of various reproductive outcomes among spouses and birth defects among children of PGW veterans and non-PGW veterans; and (3) evaluate the relationship between selected symptoms and health outcomes and certain environmental exposures in the Persian Gulf area.

The study is designed as a retrospective cohort study in which a sample of 15,000 Persian Gulf-deployed troops, stratified by military branch and unit, are to be compared to an equal number of non-Persian Gulf-deployed troops, equally stratified. Women are overrepresented, as are National Guard and Reserve members.

Because of the large sample, data collection via telephone interview was not a viable option. Therefore, in Phase I of the study, a questionnaire was mailed to each of the 30,000 veterans. To try to increase the response rate, three separate mailings were undertaken, with a second and then a third questionnaire sent to those who had not responded to the previous mailing(s). The cumulative response rate for all three mailings was approximately 57 percent.

In Phase II, an analysis of the demographic, military, and medical characteristics of those who did not respond was conducted using existing military and DVA data (Table 9).

Also during Phase II, selected self-reported data collected from the questionnaires mailed to a random sample of 2,000 PGW veterans (1,500 respondents and 500 nonrespondents) and an equal number of non-PGW veterans will be validated by using medical, hospital, military, and civilian personnel records. According to those presenting the study, agreement between questionnaire data and medical records is expected to vary depending on a given health outcome.

In Phase III, which was scheduled to start in May 1998, a random sample of approximately 1,000 PGW veterans and 1,000 non-PGW veterans and family members of both groups will be invited to 1 of 17 DVA medical centers to participate in a comprehensive medical examination and laboratory testing. The purpose of the physical examination is to provide an objective evaluation of the current health status of veterans and their family members. In addition to an extensive screening evaluation

of the overall health status of individuals, a detailed evaluation of certain organ systems will be attempted.

TABLE 9 Distribution of Selected Characteristics of Those Who Responded versus Those Who Did not Respond to DVA National Survey of PGW Veterans

	Persian Gulf Veterans		Controls	
Characteristics	Respondents (N = 8,846)	Nonrespondents (N = 6,154)	Respondents (N = 6,794)	Nonrespondents (N = 8,206)
Sex				
Male	80	80	79	81
Female	20	20	21	19
Mean age (yr) (1991)	30.8	27.9	32.6	28.5
(interquartile range)	(24–37)	(22–32)	(25–40)	(22–33)
Race				
White	75	60	78	63
Black	18	31	15	29
Others	7	9	7	8
Marital status				
Married	53	45	58	45
Single	41	50	37	50
Others	7	5	5	5
Rank				
Enlisted	85	92	79	90
Officer	15	8	21	10
Branch				
Air Force	12	10	14	10
Army	65	63	62	66
Marine	11	12	16	12
Navy	12	15	14	12
Unit component				
Active	37	44	40	40
National Guard	29	24	27	26
Army Reserve	34	32	33	33

NOTE: All data except for ages are in percentages.

The following discussion summarizes three presentations: (1) a comparison of mortality rates between PGW veterans and non-PGW veterans, (2) postwar hospitalization experiences, and (3) a report of a DVA survey of PGW veteran satisfaction.

Mortality.

In late 1996 the results of a study entitled *The Mortality Among U.S. Veterans of the Persian Gulf War* were published (Kang and Bulman, 1996). The design and results of that study were presented at the workshop by one of the authors, Dr. Han Kang. The study was designed as a retrospective (historical) cohort study comparing the mortality outcomes for all eligible PGW veterans (approximately 700,000) to the mortality outcomes for 750,000 veterans who did not serve in the Persian Gulf theater of operations. The study population was defined as all military personnel who served in the Persian Gulf theater of operations any time between August 1990 and April 1991. Controls were defined as a sample of military personnel who served in the military any time between

August 1990 and April 1991, but who did not serve in the Persian Gulf theater. The control subjects were frequency matched to the PGW veterans by branch of service and unit status (i.e., active duty, Reserve, or National Guard). For the study subjects, the follow-up of mortality began when they left the Persian Gulf theater alive. For the control subjects, the period began on May 1, 1991.

The beneficiary identification record locator subsystem (BIRLS) was used to ascertain mortality status. The BIRLS is a computerized system within DVA that includes the name and other relevant information of any veteran who has had contact with DVA regarding benefits, including death benefits. The information in BIRLS was combined with the Social Security Administration death benefit files to ascertain the status of each veteran.

Among PGW veterans, 1,765 deaths were identified through September 1993. Among the non-PGW veterans, 1,729 deaths were identified. Death certificate information was obtained for 93 percent of each group. The overall mortality rate ratio was found to be higher among the groups that had been deployed to the Persian Gulf; most of that is due to external causes, especially motor vehicle accidents. The motor vehicle accident rate ratio is 30 percent higher among PGW veterans than nondeployed troops. According to the authors, this finding is consistent with patterns of postwar mortality among veterans of previous wars.

If one compares the mortality experience of both groups of veterans to that of the general U.S. population, one finds that the veterans' mortality experience is about half that of civilian counterparts both for overall cause and for specific disease categories. These findings are consistent with the findings for other wartime veterans and is sometimes attributed to the healthy worker effect. That is, to be in the military one must meet certain physical standards, and to stay in the military one must maintain those standards.

Hospitalizations

Capt. Gregory C. Gray described the purpose of the study entitled *The Post War Hospitalization Experience of U.S. Veterans of the Persian Gulf War* as an effort to compare the hospitalizations of PGW veterans to those of non-PGW veterans to identify disease categories that would merit further investigation. The study was a retrospective cohort study that examined hospitalizations in DoD hospitals from August 1, 1991, to September 30, 1993. These dates were chosen because of the availability of data and the fairly low attrition from active-duty service.

Data for this study were obtained from the computerized databases of the DoD Manpower Data Center. They included demographic variables, military separation information, and hospitalizations. The study compared 579,046 PGW veterans who were still serving in the Army, Navy, Marine Corps, and Air Force with 618,335 other veterans from the same era who did not serve in the Persian Gulf.

A review of any cause of hospitalization and 14 different ICD-9 diagnostic categories was conducted using multivariate logistic regression models. Three separate time periods were used: August to December 1991, January to December 1992, and January to September 1993. Three ICD-9 diagnostic classifications are missing. These all involve reproductive outcomes, which were examined in a separate study. The major classifications of diseases and injuries include:

- Infection and parasitic diseases;
- Neoplasms;
- Endocrine, nutritional, and metabolic diseases;
- Diseases of the blood and blood-forming organs;
- Mental disorders;
- Diseases of the nervous system;
- Diseases of the circulatory system and sense organs;
- Diseases of the respiratory system;
- Diseases of the digestive system;
- Diseases of the genitourinary system;
- Diseases of the skin and subcutaneous tissue;
- Diseases of the musculoskeletal system and connective tissue; and
- Symptoms, signs, and ill-defined conditions.

Veterans deployed to the Persian Gulf compared to veterans not deployed to the Persian Gulf were disproportionately male (94 versus 88 percent) and younger (median age, 25 versus 27 years). They also differed, but to a lesser extent, with respect to race or ethnic group, marital status, branch of service, rank, salary, and occupation. To control for these differences, the hospitalization rate ratios were adjusted for age and sex, and the multiple logistic-regression models were adjusted for all observed demographic differences between the groups.

Initial analysis showed that PGW veterans were at slightly lower risk of hospitalization for any cause than other veterans 2 years before the war but that the risk did not differ after the war. It was hypothesized that such a transient effect exists because if a person attached to a unit that would be deployed to the Gulf injured himself or herself (e.g., broke an ankle) prior to deployment, that person would not be deployed, even though he or she would still be attached to a unit that was deployed. To control for this selection bias that resulted in the deployment of only the healthiest people to the Persian Gulf, a covariate representing prewar hospitalization was created for inclusion in the multivariate analyses.

Looking, then, at any cause of hospitalization of PGW veterans versus non-PGW veterans and controlling for all covariates, no increased risk of hospitalization was found for PGW veterans versus nondeployed veterans for any period of time examined. However, the following groups were more likely to be hospitalized after the war: females, married personnel, older personnel, Caucasians, Army personnel, medical workers, enlisted personnel, and persons with the lowest salaries. When pregnancy-related hospitalizations were excluded from the analysis, the increase in risk among deployed women and married personnel disappeared.

The hospitalization rates for PGW veterans were higher than those for non-PGW veterans for neoplasm in the first 5 months after the Gulf War and for diseases of the blood in all 12 months of 1992. A closer examination of neoplasms found that with the exception of testicular cancer most of these were benign tumors. Testicular cancer was rare, however, and PGW veterans were not hospitalized with this diagnosis more often than other veterans in 1992. With respect to diseases of the blood, closer analysis found that many of the diagnoses were related to anemia, and the increased risk was also a transient effect.

Female PGW veterans were at slightly greater risk than nondeployed veterans for urinary system diseases during the first 5 months following the war. These diseases included infertility and inflammatory diseases of the ovaries, fallopian tubes, pelvic cellular tissue, and peritoneum. An hypothesis offered by the presenter was that this brief increase might be due to a delay in seeking health care because few gynecologists were available in the Gulf. There was no increased risk in the following year.

Male PGW veterans were slightly more likely to have an intact prepuce and were at slightly higher risk for phimosis, a diagnosis frequently associated with hospitalization for circumcision. By 1993 there was no increased risk.

The only diagnostic category associated with increased hospitalizations in 1992 and 1993 was mental disorders. Specific diagnoses within this category are alcohol dependence syndrome, nondependent use of drugs, adjustment reaction, personality disorders, and neurotic disorders. According to the presenter, these findings are consistent with those in the literature regarding studies of veterans of other wars, particularly those who served in Vietnam.

Overall, during the 2 years after the Persian Gulf War, there was no excess of unexpected hospitalizations among Americans who remained on active duty after serving in that conflict. The increased risk of hospitalization among women and health care workers is consistent with the findings of a previous study of hospitalizations in the Navy conducted by A. Holberg, which was published in the *Journal of Occupational Medicine* in 1980 (Holberg, 1980). Increased rates of hospitalization because of the use of drugs and alcohol as well as readjustment problems have been seen and studied in other veterans of combat. There were some differences in risks between PGW and non-PGW veterans associated with specific diagnoses, but these differences were not consistent over time.

According to Dr. Gray, this study has a number of strengths: its large sample size of 1.2 million; the fact that a very high percentage of all hospitalizations were included because persons on active duty have little opportunity to be hospitalized outside the DoD system; and the fact that hospitalizations are an easily identifiable objective outcome. Limitations were also reviewed by the presenter. The study does not include information on hospitalizations after separation from the service, and selective separation may occur among those with medical problems. In addition, as a measure of the health of PGW veterans, the study provides little information about those illnesses that do not generally lead to hospitalization. The broad classification of outcome categories may mask important differences in the population. Finally, illnesses with a long latency would not have been included because of the short time frame of the study.

Satisfaction

Dr. Mark Meterko explained that the purposes of the DVA Health Assessment Project are to measure the functional status of veterans served by DVA by using a standardized, valid, and reliable tool; to analyze the data and disseminate the results; and to advise DVA regarding the use of feedback surveys as an indicator of disease burden and health care outcomes. Data on PGW veterans were collected in a special National Customer Feedback Survey between October 1997 and January 1998, and include subjective self-report information concerning satisfaction with the medical services provided by DVA and health-related quality of life or functional status information.

Satisfaction with specific features of care is measured with 42 multiple-choice items related to the most recent visit and care received during the previous 2 months. This portion of the survey is a derivative of a survey developed by the Picker Institute. Questions on overall satisfaction include eight multiple choice items and two open-ended comment solicitations.

Demographic and background questions include one on education and two on home health care needs. The final questions refer to reason for the visit, type of provider seen, and so forth. Also included in this database is demographic and military information obtained from the DVA outpatient visit database including age, gender, race, marital status, means test status, period of service, service connection, visit date, diagnosis, outpatient facility, home city, and home zip code.

Ten dimensions are used as indicators of quality of care, and satisfaction with these 10 dimensions is measured in this survey. These dimensions are access, information or education, preferences, emotional support, coordination of care, continuity of care, courtesy, physical comfort, family involvement, and transition.

Functional status information is based on the Medical Outcomes Study SF 36 and contains 10 multiple-choice items. Two components of functional status are measured: physical and mental.

Physical functioning questions relate to interference of physical conditions with the performance of one's daily role, bodily pain, and general health. The mental component includes questions about vitality, social functioning, the effects of one's emotional state on ability to conduct normal activities, and general mental health.

Sampling criteria for the 1997 PGW veteran survey are (1) use of DVA health care and (2) a primary care or specialty care visit between December 2, 1996, and August 2, 1997. The target quota was to have 175 PGW veterans per outpatient facility to provide feedback at the facility level. The preliminary screens identified 63,353 individuals as potential survey participants. Of these, 18 percent (11,148) did not pass the premailing address check, and an additional 11,014 (17 percent) questionnaires were returned by the U.S. Post Office as undeliverable. A loss of 35 percent due to address problems is highly unusual. The normal rate of loss is 3 to 4 percent in a general outpatient survey. This discrepancy needs to be investigated before any additional mail surveys of this population are conducted. The final survey population included just over 41,000 individuals.

The survey procedure used was a modified Dillman mail survey starting with an initial letter announcing the survey. At 1 week following the mailing of the introductory letter, the first questionnaire was mailed; follow-up reminder and thank-you postcards were mailed at week 2. At week 5 a second questionnaire was mailed to the nonrespondents, and at week 7 data collection was closed. The total response rate was 40 percent.

The results of the satisfaction survey indicate that veterans were most satisfied with courtesy and access and were least satisfied with overall coordination and continuity of care. No attempt was made to analyze satisfaction data by diagnosis or underlying reason for the health care visit, although it might be valuable to use this approach.

In examining the response to the survey on functional status, one finds that in terms of physical functioning PGW veterans are self-reporting better health than DVA national average (PGW veterans are much younger) but are very close to DVA national average on mental health.

As demonstrated by the presentations, many data systems are available and have been used to examine the health, largely defined in physiological terms, of Persian Gulf War veterans. As discussed earlier, information from these studies is limited, as suggested by the speakers, and important information such as health status and well-being prior to deployment was either not collected or unavailable. Data obtained from the CCEP or the PGR/UCAP are of limited value for research given the self-selected samples.

GULF WAR RESEARCH IN THE UNITED KINGDOM

Dr. John Graham discussed the health concerns and research efforts of the United Kingdom regarding service in the Persian Gulf. Operation Granby, the United Kingdom effort in the Persian Gulf War, deployed just over 50,000 troops. Many of those deployed were Reserve volunteers. In peacetime, British military units are only about one-third to one-half full strength. They are, therefore, augmented to bring them up to war strength.

Officials in the United Kingdom were concerned about potential health problems resulting from the possible use of chemical and biological weapons, use of nerve agent pretreatment and anthrax, plague, and pertussis vaccines and the personnel's rapid repatriation without the usual debriefing after service. In particular, the Reserves were repatriated very quickly. Reserves in the United Kingdom are usually deployed for only weeks at a time, so the several-month deployment during the Persian Gulf War was very unusual.

To facilitate the care of veterans, the Medical Assessment Program (MAP) was established in 1993. It had two objectives: (1) to provide care for veterans who were concerned that their health had suffered as a result of their participation in the Gulf War and (2) to provide to the Minister of De

fense data that would help him understand the nature of the illnesses from which veterans were suffering. To date, MAP has seen about 2,500 veterans. Psychological conditions predominate. PTSD is being diagnosed in about one-third of those being seen in the program, which is much higher than the rate of PTSD among U.S. PGW veterans.

However, not all PGW veterans are being evaluated through MAP. Once an individual is discharged from the service, he or she has access to the National Health Service (NHS). Very sick veterans were being treated by the NHS and were not seen through MAP. Therefore, the information available was not representative of the population of PGW veterans. By 1998, 50 percent of those who served in the Persian Gulf had been discharged from the military. Those veterans who had left the service had to be included in any effort to assess whether those who served in the Persian Gulf were more ill than their peers.

Unlike DoD in the United States, the Ministry of Defense (MOD) in the United Kingdom has no large epidemiological research capability. It was necessary, therefore, to involve the Medical Research Council in any effort undertaken. The following were the most important questions to be answered: (1) Are PGW veterans more ill than their peers who were not deployed? (2) If so, what are they suffering from? Finally, (3) is there an excess of adverse reproductive outcomes in the families of PGW veterans? In October 1996, after reviewing almost 40 proposals, the decision was made to fund two studies and in December of that year the MOD announced the program.

The study teams produced a collaborative plan to outline how they would work together, and in October 1997, they produced feasibility reports as to how their studies were progressing. They developed sampling strategies that ensure that the same veterans did not receive a large number of questionnaires and others received nothing. All veterans will receive one questionnaire from one of the study teams, and they stand a one in three chance of receiving a second questionnaire.

The two studies funded include one spearheaded by Dr. Patricia Doyle from the Department of Epidemiology and Population Science at the London School of Hygiene. Dr. Doyle conducted a postal survey of all 53,000 veterans and comparison groups matched by age, sex, and rank. The survey asked about reproductive outcomes and exposures. The other study was conducted by Professor Nichola Cherry of the Centre for Occupational Health at the University of Manchester, who received funding to conduct a survey of three groups of 5,000 individuals each: two groups of PGW veterans and one group of matched controls. In her cross-sectional prevalence study, she will use one group of PGW veterans to work out a case definition which she will then use to study the other group of PGW veterans and the control group to try to determine if there are differences in the levels of ill health being reported. If this is productive, she intends to proceed with a nested case reference study in which she will factor in exposure data. She is also receiving from MOD routinely reported mortality and cancer registration data.

In addition to these two studies, MOD recommended that the research effort include Professor Simon Wessley, Department of Psychological Medicine at King's College School of Medicine and the Institute of Psychiatry, who had previously been funded by DoD to carry out a study looking at veterans in the United Kingdom. That study is a cross-sectional prevalence study examining three groups of 5,000 subjects each: PGW veterans, veterans who had been deployed to Bosnia, and non-deployed controls. He intends to identify those who fall below the thresholds defining objective ill health. The second phase of the study will be a case validation phase to look for the prevalence of conditions such as asthma, depression, and chronic fatigue syndrome.

One problem encountered by the study teams is data quality. Both the demographic data and the health data from MOD need considerable quality assurance work. In addition, there has been difficulty tracing veterans. Another problem involves the reliability of exposure data.

Currently, the study teams have completed the pilot phases of their studies and are moving into the main efforts. It is hoped that initial findings will be available by the end of 1998. Collaboration between the researchers has been extremely helpful.

DATABASES

In designing a study to measure the health of PGW veterans, the committee must know what data are currently available. The following sections provide information about the existing databases of DVA and DoD.

VA Databases

Nancy Dalager of the DVA described several DVA databases that contain information that could be used to measure different aspects of the health of PGW veterans. Some of these are standard DVA administrative and medical databases, and others are databases that contain information only on PGW veterans.

The Decentralized Hospital Computer Program (DHCP) which is present in all DVA medical centers, is the electronic database system that captures all clinical and administrative data for each patient. These data can then be linked between centers and nationally. The function of DHCP is to generate hard-copy reports of such things as laboratory and radiology findings and pharmacy assignments. These are then entered into an individual's medical record.

Although DHCP performs well the functions for which it was designed, it is of limited value for researchers conducting retrospective analyses because many facilities regularly purge their data. At some facilities laboratory and pharmacy data are purged every 90 days. Some data are purged annually. The DHCP serves as a source of data for the Veterans Information Systems Technology Architecture (VISTA), which is generated at the DVA Austin Automation Center.

The national patient care databases are Patient Treatment Files (PTFs) and the Outpatient Care Files (OPC). Within the PTF are four types of patient-specific PTFs that contain medical and demographic information about each episode of inpatient care: (1) Main, (2) Bed Section, (3) Procedures, and (4) Surgery.

The **Main** file contains demographic and summary information on each episode of care and up to 10 diagnostic codes (ICD-9). Until October 1994, the diagnosis that generated the longest hospital stay was coded as the primary diagnosis. This was changed, however, so that the field now contains the principal diagnosis, that is, that diagnosis determined by the physician to be responsible for the patient's admission to inpatient care.

The **Bed Section** file holds diagnostic and length-of-stay data for each bed section. It is patient-specific, and all the files are linked by a scrambled Social Security Number to preserve privacy.

The **Procedures** file is a per-day record of the procedures that have been performed for that particular patient, and the **Surgery** file includes specifics about the surgery data.

A second major national database is the OPC files. These files contain three types of patient-specific files that document a day of outpatient care: (1) Standard, (2) Ambulatory Procedure File, and (3) Diagnostic File. The **Standard** file contains demographic, administrative, and summary information regarding clinic visits. The **Ambulatory Procedure File** has basic summary data from the Standard File plus procedural codes (CPT codes) for each clinic stop. New to the outpatient care file is the **Diagnostic File,** which was implemented in 1997 and which includes the primary diagnosis and up to nine additional diagnoses. These files are constructed so that there can be multiple records per visit day since a single record will not always accommodate all the activities in which a veteran might engage in a single day.

The Persian Gulf Registry database contains information on PGW veterans who have participated in the special diagnostic program established by DVA. As of March 1998, this database contained information on 66,918 PGW veterans. There are two distinct formats: one contains data on those PGW veterans seen prior to the code sheet revision and the other contains data for those seen

after the revision. Both formats contain information on self-reported symptoms, diagnoses, and self-reported exposures. Routine tabulations of symptom, diagnostic, and exposure information are prepared with these data.

As tabulations and comparisons were made between PGW veterans and non-PGW veterans, it became clear that specific definitions of each group were needed to ensure that all investigators were using the terms consistently. Therefore, the following definitions were developed. *Conflict veterans* are those who served in the Persian Gulf any time between August 1990 and July 1991. *Theater veterans* are those who served in the Persian Gulf theater of operations any time after July 1991. *Era veterans* are those who were in the service at the time of the Persian Gulf conflict or have served since then but who were never deployed to the Persian Gulf theater. DVA has identified 696,530 conflict veterans, almost 400,000 theater veterans, and about 2.3 million era veterans.

Within the past year, the DVA Environmental and Epidemiology Service has been asked to generate and maintain a consolidated DVA and DoD Persian Gulf Registry. The objective of this project is to create a single standardized database that contains all the information from both the DVA and the DoD registry programs. This consolidated project would involve three existing computerized databases: the Defense Manpower Data Center's roster of PGW veterans, the data from DoD CCEP, and data from DVA PGR/UCAP. This combined database could be used to identify a group of veterans for further study of health status, medical conditions, or self-reported exposures.

As Ms. Dalager pointed out, because there is considerable variation in data collection procedures both within DVA and within DoD, as well as between DVA and DoD, it is difficult to make any meaningful comparisons with respect to medical data. To date no mechanism for generating combined tables has been developed, and data are displayed separately for CCEP and PGR/UCAP. It is believed, however, that this database provides a valuable resource for identifying cohorts of PGW veterans who have experienced a similar array of symptoms or diagnostic evaluations and, therefore, who could serve as a starting point for more in-depth research studies.

It is important to note when using these data that the systems were not designed to provide research-quality information. Any attempt to use the data for research purposes would require careful assessment of the reliability and validity of the information.

DoD Databases

LTC Mark Rubertone described relevant DoD data systems. Within the Army Center for Health Promotion and Preventive Medicine (CHPPM) is the Directorate of Epidemiology and Disease Surveillance, which has two major sections. One section is the Epidemiology Division and the other is the Army Medical Surveillance Activity (AMSA). DoD has amassed the databases that it believes are useful for tracking the health and disease of active-duty service members. AMSA maintains the (1) Defense Medical Surveillance System (DMSS), (2) DoD serum repository, (3) Defense Medical Epidemiology Database (DMED), and (4) the Medical Surveillance Analysis Contract.

The at-risk population for whom most comprehensive data are available is the active-duty population. These data are housed in the DMSS, which contains information from preinduction (including the initial human immunodeficiency test [HIV] test, and limited medical information from the military entrance processing station [MEPS]) to postdischarge. Many databases will ultimately be linked through DMSS including MEPS data, HIV test results, assignments and deployments, inpatient hospitalizations, ambulatory data, reportable diseases, Health Risk Assessments, and pre-and post-deployment specimens and surveys.

The inpatient hospitalization and ambulatory data are on-line. The reportable disease data are being collected independently by each service, but DoD is working to implement a triservice (Army, Navy [including Marines], and Air Force) reportable disease database. Health risk assessment has

been an Army-only system that has included behavioral risk factors, smoking, alcohol use, seat-belt use, exercise, and so forth. It will eventually be superseded by the Health Enrollment Assessment Review (HEAR) developed by the Air Force. HEAR data are expected to become part of DMSS.

Environmental exposure information is not currently a part of the database. CHPPM maintains information on environmental exposures for deployment, but it is typically not population-based and cannot be linked with individuals.

Dr. Rubertone pointed out that DMSS depends on these outside data sources because it does not engage in primary data collection. The only check on the accuracy of the data is comparison of data from one source with data from another source. A good example of this is inpatient data. About 10 percent of all inpatient hospitalizations for the active-duty population turn out to be individuals not on active duty, that is, members of the Reserve or National Guard who have been admitted and miscoded.

The DMSS database contains information on more than 6 million individuals: all those on active duty, in the Reserve, or in the National Guard for all five services (Army, Navy, Air Force, Marine, and Coast Guard). Accompanying these data are the demographic data such as assignment locations at specific points in time, military occupational specialty, marital status, and grade.

Because all these data are on-line in an Oracle®-based system, it is possible to link databases and files very quickly. For example, one can query the system to examine hospitalizations for infectious and parasitic diseases in those deployed to Somalia versus hospitalizations for a control group matched by age, sex, and length of time in the service. This query was made and a bar graph was created. The bar graph showed that in the year prior to the Somalia deployment, the rates of hospitalization were about the same for the two groups. In the year following deployment, however, there was a much increased rate of hospitalization for the deployed group.

DMSS is designed to allow one to obtain fairly rapidly a picture of the incidence of a particular variable over time and compare that incidence in two or more groups.

DMED is a prototype system that provides the public with remote access to DMSS but does not permit the identification of individuals. It attempts to integrate the epidemiological capabilities of the Army, Air Force, and Navy into one system by using a standard methodology and standard data elements. The Phase I prototype includes longitudinal personnel data and hospitalizations for active-duty personnel. It is DoD's intent to expand the data sources to include ambulatory data, reportable diseases, and deployment information.

THE HEALTH OF PATIENTS IN THE SPECIALIZED CARE PROGRAM.

The Specialized Care Center at the Walter Reed Army Medical Center was established in March 1995, to evaluate, treat, and rehabilitate active-duty personnel who are suffering from chronic debilitating symptoms. About 150 veterans of the Persian Gulf War have participated in this intensive 3-week program designed to aid patients in resolving issues that result in dysfunction or impairment.

LTC Charles Engel described the often different perspectives of the patient and the clinician in defining health. According to Dr. Engel, the clinician proceeds along relatively biomedical lines and gathers subjective or historical information about how the patient feels and objective information based on examination and testing. He or she then assesses the patient's condition and decides whether to develop a treatment plan, which in effect validates the patient's complaints or rejects the complaint as not valid.

Illness from the patient's perspective, suggests Dr. Engel, involves three basic components: the perception of symptoms as a biological phenomenon; a cognitive aspect that includes the patient's beliefs and ideas about what that symptom means; and a behavioral aspect that includes functional limitations, reports of symptoms and suffering, and health care use. Research on the health status of

PGW veterans must take into account the fact that health beliefs and reports of physical symptoms are meaningful events for the veterans.

Dr. Engel believes that, when conceptualizing a design to measure the health of PGW veterans, it is important to consider that current stressors may be important determinants of current health status and are perhaps even more important than the stressors experienced during the war. The domains of stress that could be considered in monitoring the longitudinal health of PGW veterans include distress that is reported to be a consequence of war experience, distress that is associated with current bodily experiences, distress about Gulf War health information, beliefs about possible Gulf War related health problems or a possible undiagnosed illness, and distress about behavioral limitations. Key health behaviors that indicate levels of stress include alcohol use and related difficulties, drug use (both illicit or recreational and prescription drug use) and related difficulties, tobacco use, and amount, type, and frequency of exercise. It is also important to take into account, at least for active duty military personnel, the fact that this is an occupational health care setting in which many feel that the data collected are provided to the military and can have an effect on one's future career path.

In measuring health status Dr. Engel proposed that one might also wish to examine the quantity and type of health care service use, the use of informal care (e.g., chaplain), the global satisfaction with care, whether perceived needs were met, and iatrogenesis or problems due to excessive or inappropriate health care.

DRAFT PROTOCOL

In 1997 DoD began exploring the feasibility of conducting studies to evaluate the current well-being of CCEP participants among specific diagnostic groups and to evaluate the treatment received as a result of examination through CCEP. Dr. David Cowan presented, for discussion, a preliminary research protocol.

The study sample was to be CCEP participants from selected diagnostic categories. The diagnostic categories chosen were mental disorders (ICD-9 codes 290 to 319); symptoms, signs, and ill defined conditions (ICD-9 codes 780 to 799); musculoskeletal system and connective tissue diseases (ICD-9 codes 710 to 739); and individuals with a complaint but for whom no diagnosis was made (ICD-9 codes V65.5). A fifth study group consisting of randomly selected CCEP participants was included in the hope that this would permit the findings of current health status to be generalizable to the entire CCEP population.

Initial plans were to compare each diagnostic group to each of two comparison groups: a sample of PGW veterans who have not participated in the CCEP and a sample of nondeployed veterans who were serving in the military during the period of the Persian Gulf War. Workshop participants agreed that because these groups will not be matched to the study sample on the basis of diagnosis, any comparisons that can be drawn will be questionable.

Surrogate measures of health, such as retention on active duty and the receipt of veterans' benefits, were to be developed and used as measures of health and well-being. Direct measures of health and well-being were to be obtained from telephone interviews with the study subjects and were based on the responses to validated standard interview questionnaires.

Workshop discussion elicited a number of concerns about the value of the results obtained from the study described in the draft protocol. Foremost among these questions is, What would be the value of such a study? Most (535,000) of those who served in the Persian Gulf War have left active duty and would not be included in the study. Those who remain on active duty would tend to be healthier individuals. Any results obtained by using the draft study protocol would not be applicable to the general population of Persian Gulf veterans.

If the question that one is attempting to answer is how PGW veterans are doing physically compared to veterans not deployed to the Persian Gulf War, one cannot rely on data from CCEP alone to answer that question. Even if one were to include those who have been seen as part of the DVA PGR/UCAP, these are self-selected populations who have identified themselves as being ill.

Assessment of treatment effectiveness would also be difficult because the diagnostic groups chosen are very broad and the subjects in each group have many different diagnoses. The assumption in the draft proposal is that if a veteran received a diagnosis as part of the CCEP or PGR/UCAP, he or she then followed through and received help for that condition. That is not necessarily the case. Added to this problem is the fact that treatment, if it is being provided, is being provided in hundreds of facilities by hundreds of different health care providers without the use of standardized treatment protocols.

Assessment of treatment appropriateness might be an easier task. The diagnostic groups chosen are very broad, however, and the subjects in each group have many different diagnoses. The diagnoses would need to be much more specifically defined to assess the adequacy of the treatment provided.

OPEN TESTIMONY

The final component of the workshop was devoted to public testimony. One individual, Albert Donnay, executive director of MCS Referral and Resources in Baltimore, Maryland, presented information to the committee. The following is a summary of his presentation.

According to Mr. Donnay, any assessment of the current health status of PGW veterans will depend on the ability of DVA and DoD to screen reliably for and diagnose the health problems of these veterans, especially chronic fatigue syndrome, fibromyalgia syndrome, and multiple chemical sensitivity. Mr. Donnay discussed a 10-item questionnaire that could be used to screen for these conditions and reported that studies have shown that there is a tremendous overlap of symptoms among patients diagnosed with chronic fatigue syndrome, fibromyalgia syndrome, and multiple chemical sensitivity. He also reported that unpublished studies to which he had access have found a high incidence of these conditions among PGW veterans. Mr. Donnay asked that the committee recommend that "any future DoD or DVA evaluations of the health status of personnel who served in the Gulf War include routine screening for chronic fatigue syndrome, fibromyalgia syndrome, and multiple chemical sensitivity according to standardized diagnostic criteria."

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Conclusion

The information obtained from the presentations and discussion during the workshop serves as an important base of knowledge for the committee as it proceeds with its charge to develop a study design(s) and methods that could be used to measure the health of PGW veterans over the long term. The committee thanks those who were willing to participate in this first step of the new IOM study on *Measuring the Health of Persian Gulf War Veterans.* Much additional information and research is yet to be reviewed, analyzed, and discussed before any final decisions are made, but the workshop has begun the process that will result in a final report and recommendations by the committee.

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Appendix Workshop on Measuring the Health of Persian Gulf Veterans

NATIONAL ACADEMY OF SCIENCES
INSTITUTE OF MEDICINE
May 7, 1998
Foundry Building, Room 2004, Georgetown
Agenda

Thursday, May 7, 1998

9:00 a.m.	Introduction and Overview
9:15 a.m.	Panel—Description of Persian Gulf Veterans' Health Problems
	• DoD data—COL Bruce Jones
	• The VA View—Frances M. Murphy, M.D.
	• Discussion
10:15 a.m.	BREAK
10:30 a.m.	Panel on Completed Population-Based Studies
	• Iowa Study—David Schwartz, M.D.
	• VA Research Activity—Han K. Kang, Dr. P.H. Includes Mortality study and Survey
	• Naval Research Center Activity—Greg Gray, M.D. Includes Hospitalization study
11:30 a.m.	Discussion
12:00 p.m.	LUNCH
1:00 p.m.	British Research
	COL John T. Graham

1:30 p.m.	Open Testimony
	Each person will be allotted 5 minutes—more if there is time
2:30 p.m.	Panel on Databases
	• DoD—LTC. Mark Rubertone, M.D.
	• VA—Nancy A. Dalager, M.S.
	• Patient Survey—Mark Meterko, Ph.D.
	• Discussion
3:30 p.m.	BREAK
3:45 p.m.	Reflections on Health Status Measurement—Perspective of the Specialized Care Program
	MAJ Charles Engel, M.D.
4:15 p.m.	Group discussion of DoD "straw man" proposal
4:45 p.m.	Discussion
5:30 p.m.	Adjourn

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