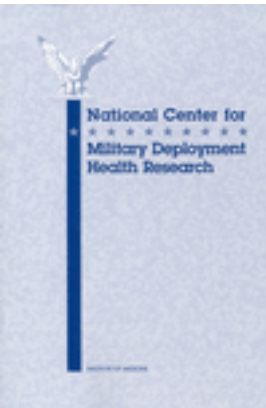

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National Center for Military Deployment Health Research

Lyla M. Hernandez, Catharyn T. Liverman, and
Merwyn R. Greenlick, *Editors*

Committee on a National Center on
War-Related Illnesses and Postdeployment Health Issues

Division of Health Promotion and Disease Prevention

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The image adopted as a logotype by the Institute of Medicine is based on a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

COMMITTEE ON A NATIONAL CENTER ON WAR-RELATED ILLNESSES AND POSTDEPLOYMENT HEALTH ISSUES

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This report has been reviewed in draft form 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 institution 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 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:

Margit L. Bleecker, Center for Occupational and Environmental Neurology, Baltimore, MD
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While the individuals listed above have provided constructive comments and suggestions, it must be emphasized that responsibility for the final content of this report rests entirely with the authoring committee and the institution.

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Executive Summary

Concerns about the health of veterans of recent military conflicts have given rise to broader questions regarding the health consequences of service in any major military engagement. The Veterans Program Enhancement Act of 1998 directed the Secretary of Veterans Affairs to enter into an agreement with the National Academy of Sciences to help develop a plan for establishing a national center (or centers) for the study of war-related illnesses and postdeployment health issues. In response to this legislation, the Department of Veterans Affairs (VA) asked the Institute of Medicine (IOM) to convene a committee of experts. The charge to the committee was to (1) assist the VA in developing a plan for establishing a national center (or centers) for the study of war-related illnesses and postdeployment health issues, and (2) assess preliminary VA plans and make recommendations regarding such efforts.

The IOM convened the Committee on a National Center on War-Related Illnesses and Postdeployment Health Issues, composed of experts on war-related illnesses, clinical research, military medicine, epidemiology, health services research, operations research, development of interdisciplinary research centers, research ethics, technology transfer, and the integration of clinical and education programs with research. Between January and September 1999, the committee met three times. The first meeting included a workshop that was held to obtain background information on relevant issues. During subsequent meetings, the committee reviewed information on war-related illnesses and relevant research activities, analyzed alternative models for national research centers, and received testimony from veterans about their views for such a center. Additionally, the committee examined the VA's proposal for developing a national center program within the VA.

The committee conducted its deliberations with an understanding that the nature of military engagement has changed. Contemporary military conflicts

depend on the availability of smaller expeditionary forces that maintain a high level of military readiness. This greater reliance on readily deployable forces includes increased participation by guard and reserve members. Both active-duty, guard, and reserve forces experience profound life disruptions connected to all phases of deployment that, despite the relatively rapid and short-term experience, may have long-standing health consequences. Additionally, there is a component of deployed civilian workers who are similarly impacted by military deployment. The committee found that:

- Extensive research exists on the health of veterans of military conflict.
- The definition of deployment-related health issues selected for research has been too narrowly focused and has excluded some health consequences related to deployment.
- There are gaps in the emerging data relevant to the study of war-related illnesses and postdeployment health issues.
- Many investigations of health issues and effects of deployment have been mounted in response to health problems after they occurred, rather than being undertaken proactively.
- Many veterans and some congressional staff are skeptical of the objectivity of both the Department of Defense (DoD) and the VA in the conduct of research into deployment-related health issues.
- None of the locations of existing or proposed centers provides an adequate model for a national center that not only must be responsible for the conduct of a broad range of research but also must provide for synthesis and coordination of research efforts and for proposing policy changes based on research findings.
- Examples exist of centers that cut across agencies and groups to carry out effective research agendas.

VA PROPOSAL

One component of the committee's charge was to review the VA's proposal to establish Centers for the Study of War-Related Illnesses and Postdeployment Health Issues by using the model of the Geriatric Research, Education, and Clinical Centers (GRECCs). The GRECC program has been successful in training health professionals, conducting cutting-edge research, and implementing effective treatment programs. Creating centers based on this model for the study of deployment-related health should contribute greatly to the advancement of knowledge in this area. Therefore, **the committee recommends that the Department of Veterans Affairs proceed with its proposal to establish centers for the study of war-related illnesses, and that these centers be similar in structure to the Geriatric Research, Education, and Clinical Centers.**

NATIONAL CENTER

The second component of the committee's charge was to make recommendations regarding a national center. The committee concluded that a national center could provide the needed mechanism to coordinate and synthesize the ongoing research efforts. Such a center would be in a position to provide an overarching research agenda that would identify gaps in current research, to coordinate existing and future research, to focus the infusion of new research funding, and to recommend policies related to such research. Therefore, **the committee recommends that Congress establish a National Center for Military Deployment Health Research that will focus on the health of active, reserve, and guard forces, and veterans and their families.**

Location of the National Center

Despite the anticipated contributions of the VA centers, location within the VA carries with it limitations for a national center that is responsible for coordinating and synthesizing research across federal agencies and in university-based settings. The committee examined a number of options for the location of the National Center and concluded that it should be independent of governance by any single federal agency in order to foster scientific excellence and assure scientific and public accountability. Therefore, **the committee recommends that the National Center be placed under the auspices of and report to the Military and Veterans Health Coordinating Board (MVHCB). Further, the committee recommends that the National Center replace the Research Working Group of the MVHCB.**

The MVHCB was established by Presidential Review Directive and is chaired by the secretaries of the Department of Defense, the Department of Veterans Affairs, and the Department of Health and Human Services (HHS). It is charged with providing "oversight, coordination, and linkages to other related efforts in the Federal Government in the areas of deployment health, health care, research, health risk communication and education, record keeping, and compensation." The MVHCB has a broader mission than is found in any single federal agency and has been mandated to foster collaborative effort.

The Research Working Group (RWG) of the MVHCB has been charged with providing recommendations and coordinating research activities on deployment health issues affecting active-duty members of the armed forces, veterans, and deployed civilians, as well as the families of these individuals; preventing unnecessary duplication of research and assuring that resources are directed toward high-priority studies; and with acting as a forum for information exchange within the research community at large and for research coordination among the three participating departments. Since the proposed National Center for Military Deployment Health Research will encompass all aspects of the Re-

search Working Group's mission, the committee suggests that the new Center replace the RWG, rather than duplicate its efforts.

Structure of the National Center

The committee envisions three key structural components for the National Center. These components are:

- a Governing Board, composed of members of relevant constituencies, with responsibility for coordination and agenda-setting, as well as for oversight of the work of the Center;
- a Research Network that integrates research efforts in DoD, VA, HHS, universities, and other sites; and
- a core of specific functions, with appropriate staff to implement such functions, under the overall direction of the Center's board and the MVHCB director.

To assure the public, Congress, the scientific community, and others that all efforts of the Center are being conducted with the highest scientific integrity and public accountability, oversight of the Center should be by a Governing Board composed of representatives from a broad range of relevant constituencies. Therefore, **the committee recommends that the National Center Governing Board be composed of:**

- **three representatives each from VA, DoD, and HHS;**
- **six independent representatives from the research community; and**
- **six representatives from the community at large, including veterans and their families and the general public.**

Additionally, **the committee recommends that an independent scientific entity nominate, for both the research-community and the community-at-large positions, twice the number of candidates as there are positions available.**

The committee recommends that the functions of the Governing Board include:

- **development of a coordinated research agenda;**
- **commissioning of new research;**
- **creation of policies for the conduct and dissemination of Center research;**
- **evaluation of the output and productivity of Center research;**
- **development of policy recommendations that emerge from Center research;**

- **development of the Center's proposed annual budget; and**
- **preparation and transmittal to Congress of an annual report.**

The committee has designed the research network of the National Center with two major components: (1) federal research programs and (2) Center-initiated research. This structure provides minimum disruption to the ongoing research activities while adding a needed mechanism for research priority-setting and coordination, for dissemination of research results, and for undertaking tasks most appropriate for a central organization. Therefore, **the committee recommends a broad-based Center-initiated research program that would solicit proposals from federal agencies, universities, and other research sites and that would be managed by the National Center.**

Center-initiated research should be implemented through the announcement of a set of Requests for Applications (RFAs) and Requests for Proposals (RFPs). It is suggested that the National Center enter into an agreement with the National Institutes of Health (NIH) to use the NIH peer-review process, to the extent possible, to assess the scientific merit of the applications and proposals. The final research funding decisions remain, however, the prerogative of the Center's Governing Board.

The committee recommends that the National Center be responsible for the four core activities:

- **research coordination and priority setting;**
- **research-related policy analysis;**
- **review and analysis of longitudinal monitoring of deployment-related health; and**
- **facilitating the use of national data sources for deployment health research.**

To foster research coordination and priority-setting, the Center should sponsor conferences and workshops to gather input for the research agenda and to encourage collaborative exchange. To increase scientific input in the development of the research agenda, the Governing Board may establish advisory groups or use other mechanisms to receive technical advice. It is anticipated that as the Center grows, so will its need for additional mechanisms to accomplish its activities. Rather than attempt to dictate those mechanisms, however, the committee believes it is important to allow the Board and staff to devise their own creative responses to their future needs.

Developing policy recommendations based on research results requires the synthesis and analysis of relevant research. Some of the same mechanisms described above for use in agenda-setting can be employed in policy analysis.

The committee identified the need for a mechanism to monitor the longitudinal health of active-duty, reserve, and guard forces that goes beyond the self-selected service members who participate in DoD and VA registries. A recently released IOM report (IOM, 1999) describes a research portfolio and longitudinal

cohort study that could provide a model for a long-term tracking system of the health of veterans of military conflict. It is appropriate that the research described in that report fall within the purview of the National Center and become a cornerstone for its longitudinal monitoring efforts.

Given the numerous and varied data relevant to research on deployment-related health, the National Center should develop a process by which these data can be identified, inventoried, and described. Such activity will foster the effective use of these data.

Funding the National Center

The research issues involved in deployment-related health are complex and require long-term commitment if productive results are to be achieved. Significant funding resources will be needed for the National Center core activities, Governing Board, and Center-initiated research. The Center should propose a budget detailing the resources needed, and this budget should be a line item in the budget of the MVHCB. The Center should include such budget information in its annual report to Congress in order to provide that body with information about the functioning and productivity of the Center. Therefore, **the committee recommends that the National Center should have a clear and distinct budget for its core activities and its Center-initiated research. Further, this budget should be a line item in the budget of the MVHCB.**

CONCLUSION

Many have begun to ask whether there are health consequences of service in military conflicts beyond the obvious war injuries and, if so, whether there are ways to prevent or at least mitigate the consequences of war-related illnesses and deployment-related health effects. Congress directed that the Department of Veterans Affairs contract with the National Academy of Sciences to assist in developing plans for a national center (or centers) for the study of war-related illnesses and postdeployment health issues that could focus research on answering these questions.

The committee has recommended the establishment of a National Center for Military Deployment Health Research, to be governed by an independent board composed of representatives of the scientific community, the veterans' community, and relevant federal agencies. Such a center would provide an opportunity to gather together the results of many individual efforts, to analyze and synthesize what this research can reveal, and to move the nation forward in ways that will help and protect those individuals who will participate in future deployments.

The committee urges that the recommendations in this report be implemented as rapidly as possible in order to gain much-needed knowledge about how best to protect and treat the men and women who participate in military deployments.

1

Introduction

A large body of research exists on the health effects of military conflicts, from the U.S. Civil War through the recent conflicts in the 1991 Gulf War and Bosnia. Research on the effects of mustard gas and Agent Orange has contributed greatly to knowledge about the health problems associated with exposure to such agents. Following the end of the Gulf War in 1991, a new wave of research on the effects of that war was begun.

Information obtained from the numerous studies of veterans of specific conflicts has given rise to broader questions regarding the consequences of service in any major military engagement. Concern now is being focused on questions of war-related illnesses and postdeployment health issues, with the ultimate goal of finding ways to prevent, or at least mitigate, the consequences of such potential problems. One approach being considered is the establishment of a national center for the study of war-related illnesses and postdeployment health issues.

The Department of Veterans Affairs asked the Institute of Medicine to assist the VA in developing a plan for establishing a national center (or centers) for the study of war-related illnesses and postdeployment health issues, as well as to assess preliminary VA plans regarding such efforts. To conduct this study, the IOM convened a committee composed of experts on war-related illnesses, clinical research, military medicine, epidemiology, health services research, operations research, development of interdisciplinary research centers, research ethics, technology transfer, and the integration of clinical and education programs with research.

The committee held three meetings, the first of which included an information gathering workshop (Appendix A); reviewed and discussed published research and information about war-related illnesses and postdeployment health issues; examined various approaches to evaluate and fund national centers; identified key elements necessary for development and implementation of such centers; and developed its recommendations.

STRUCTURE OF THE REPORT

Chapter 2 summarizes information analyzed by the committee. Chapter 3 presents the committee's findings. Chapter 4 describes the committee's recommendations for development of a National Center for Military Deployment Health Research. In addition, this chapter assesses the VA's plans for proposed centers to study war-related illness and postdeployment health, develops an overview of the purpose and scope of a National Center, analyzes options for organizational structure and placement, and discusses the need for adequate funding and support. The final chapter summarizes the report and provides the committee's conclusions.

2

Background

This chapter* summarizes information upon which committee deliberations were conducted. As a starting point, the committee held a workshop in March 1999 (Appendix A). During subsequent sessions members reviewed relevant scientific literature, received testimony regarding previous research on deployment health issues, and examined the legislative history of the congressional request for this Institute of Medicine study. The committee also reviewed the charter for the newly designated Military and Veterans Health Coordinating Board. Representatives of veterans' organizations shared their perspectives on the goals for a national center to study war-related illnesses and postdeployment health issues. Further, the committee explored a number of potential center models by examining the ongoing center activities in the DoD, the VA, and the National Science Foundation's Engineering Research Center Program.

WAR-RELATED ILLNESSES AND POSTDEPLOYMENT HEALTH

Much has been learned from the rich literature examining adverse health effects of military conflicts. Elder and colleagues (1997) conducted a longitudinal study of the health effects of experiences during World War II. They examined how well-being changed across the postwar years and varied by prewar individ-

*Information presented in this chapter was based in part upon workshop presentations by Craig Hyams, Ralph Ibson, Susan Edgerton, William Cahill, Kim Lipsky, James Riddle, Charles Engel, Karl Friedl, Frank Garland, Frances Murphy, Han Kang, Matthew Friedman, Tim Gerrity, Marsha Goodwin, William Brew, Matthew Puglisi, Paul Sullivan, and Lynn Preston.

ual attributes. Their results indicated that, after controlling for the effects of self-reported physical health at war's end and for age, exposure to combat predicted a subject would experience physical decline or death during the postwar interval from 1945 to 1960. Rank and theater of engagement were of little consequence, and self-worth before the war did not moderate the risk of physical decline or death that was associated with combat.

A study of Australian veterans of the Vietnam conflict (O'Toole et al., 1996) found that combat exposure was significantly related to reports of recent and chronic mental disorders, recent hernia and chronic ulcer, recent eczema and chronic rash, deafness, chronic infective and parasitic disease, and chronic back disorders, as well as to symptoms and signs of ill-defined conditions.

Two major contributions to the investigation of war-related illnesses resulted from research into the health problems of Vietnam veterans: (1) the development of case criteria and a label for posttraumatic stress disorder (PTSD); and (2) a "model" for thinking about the long-term health consequences of a specific exposure (Agent Orange), despite the absence of an acute response. While PTSD was not new, recognition of it and the eventual incorporation of PTSD into both ICD-9 (*International Classification of Diseases*, 9th revision) and DSM-III (*Diagnostic and Statistical Manual of Mental Disorders*, 3rd ed.) dates from the Vietnam era. Research on the effects of Agent Orange used in Vietnam also is enriching the understanding of health problems experienced as a result of participation in that conflict.

Other reported health problems are less well-defined and include poorly understood, multisymptom clusters. The literature regarding such reports was summarized by Hyams and colleagues (1996). They found that during the U.S. Civil War, the numerous reported health problems could be separated into two unique illnesses: irritable heart (first identified by J. M. DaCosta) and nostalgia. Irritable heart had no specific sign or pathology and was characterized by shortness of breath, palpitations, chest pain, headache, diarrhea, dizziness, and disturbed sleep. Dr. DaCosta hypothesized that this disease was caused by either an infectious process or strenuous military duties.

The second illness, nostalgia, which is sometimes referred to as an early form of PTSD, most often affected the youngest Civil War soldiers, those 15 and 16 years old. Nostalgia was characterized by excessive thoughts of home, as well as by apathy and loss of appetite. Some of those affected also had diarrhea or chronic fever. As with irritable heart, there were no characteristic signs. Unlike irritable heart, which was thought to be a physiologic disease, nostalgia was attributed to psychological factors.

During World War I, irritable heart, commonly referred to as effort syndrome, again became an issue when soldiers reported experiencing the same symptoms, still with no characteristic sign or pathology. The condition was thought to be due to multiple factors, including strenuous military duties, exposure to poison gas, infectious diseases, and psychological distress.

Another illness experienced during World War I was called shell shock, now known as acute combat stress reaction. Its symptoms included a dazed or

detached manner, blindness, and paralysis. A number of somatic symptoms also were associated with this illness and, by the end of the war, shell shock clearly was thought to be caused by stress.

Effort syndrome was reported again during World War II. A clinical case study conducted in 1940 by cardiologist Dr. Paul Wood concluded that the syndrome was not a physiologic disease, but rather was due to psychological factors.

During the Korean War, acute combat stress reaction (also referred to as battle fatigue, operational fatigue, or combat exhaustion) was reported. It was associated with the symptoms of fatigue, shortness of breath, palpitations, headache, diarrhea, disturbed sleep, forgetfulness, and difficulty concentrating. Its cause was thought to be stress (Hyams et al., 1996).

Health problems reported following the Gulf War include a wide variety of symptoms similar to those found in acute combat stress reaction, PTSD, and chronic fatigue. To date, no research or investigation of reported health problems has identified a single etiologic entity to account for these symptoms, and no generally accepted diagnostic label or clear set of clinical criteria has been developed to use in the assessment of health problems of veterans of conflict.

Ursano and Norwood (1996) wrote that "[U]nderstanding the demands of war requires broad conceptualization of the biological, psychological, and sociocultural events involved in moving from anticipation of war to reintegration home." Charles Engel also takes a broad conceptual view of the health problems of those deployed to conflict. According to Dr. Engel, physicians often take the view that if the latest technology and tests do not show a problem, there is no problem. There are many situations in clinical medicine, however, where one deals with things that do not fit such a clearly defined diagnosis. It is necessary to pursue these medically unexplained areas to fully address war-related illnesses and postdeployment health concerns of veterans.

In addition to research being conducted on the postwar health of veterans, there are studies of specific groups within civilian populations (e.g., police, firefighters, and emergency personnel) that may contribute to the understanding of the effects of traumatic situations on individuals at risk. While the nature of the risks differs, results of these investigations may contribute important information to those who are studying the effects of war on the health of veterans, and vice versa.

LEGISLATIVE HISTORY

A major impetus for the establishment of a center to study war-related illnesses and postdeployment health issues came from the veterans' community, which proposed that Congress consider establishing a national center to study the health problems of veterans of conflict. On April 23, 1998, the Subcommittee on Health of the U.S. House of Representatives Committee on Veterans' Affairs held a hearing to receive input on draft legislation to establish a center

for the study of war-related illnesses. The proposal for such a center included three main functions:

1. promote the training of health care and related personnel in, and research into, the causes, mechanisms, and treatment of war-related illnesses;

2. serve as a resource center for, and promote and seek to coordinate the exchange of information regarding, research and training activities carried out by the VA, DoD, and other federal and nonfederal entities; and

3. coordinate with DoD and other interested federal departments and agencies in the conduct of research, training, and treatment and in the dissemination of information pertaining to war-related illnesses.

Testimony presented during the hearing supported the establishment of such a center. Dr. Matthew Friedman, Director of the National Center for Post-Traumatic Stress Disorder, suggested that such a center should become a repository of data related to deployment health and environmental surveillance, with close coordination between the VA and DoD to assure timely transfer of information. Several witnesses testified that such a center should be multidisciplinary and that coordination with the DoD was essential (U.S. House of Representatives, 1998).

H.R. 3980 was subsequently introduced; it directed the VA to establish a multidisciplinary National Center for the Study of War-Related Illnesses to carry out and foster research, education, and improved clinical care of war-related illnesses. The committee report accompanying H.R. 3980 concluded that evidence suggests combat experience is a significant risk factor in developing subsequent illness and that early treatment of war-related illness therefore is important in avoiding chronic illness. The report underscored the importance of increasing understanding of war-related illnesses and of ensuring that the VA is better prepared to treat veterans of future wars or military combat.

Meanwhile, the Committee on Veterans' Affairs of the U.S. Senate was pursuing a different approach. In the spring of 1997, the committee had initiated a bipartisan special investigation of Gulf War illnesses by a team of experts. During the course of that investigation, questions were raised about the ability of the DoD and VA to collect adequate information about, keep good health records on, and produce reliable and valid data to monitor the health care and compensation status of ill Gulf War veterans. Additionally, it was perceived that because public confidence and trust in these agencies was low, the value of the center might be impaired if it was housed or run by either department. The suggestion was made that the VA and DoD were not appropriate places to establish a center for the investigation of war-related illnesses.

Acknowledging these concerns but also suggesting that such a step requires careful study and thoughtful deliberation, Senator Rockefeller introduced legislation requiring the Secretary of Defense to enter into an agreement with the National Academy of Sciences, or another independent organization, to assess the feasibility of establishing, as an independent entity, a National Center for the

Study of Military Health. In introducing the legislative amendment, Senator Rockefeller stated, "[A]s ranking member of the Committee on Veterans' Affairs, there have been too many times when I have heard agency officials testify that poorly understood, unexplained illnesses are a common, inevitable occurrence of every military conflict. . . . I find the acceptance of these illnesses as an inevitability to be unacceptable. I hope that this amendment will offer an initial step to better prevention and treatment of these postconflict illnesses" (U.S. Senate, 1998).

The Center for the Study of Military Health envisioned in this legislation was to:

- evaluate and monitor interagency coordination on issues relating to postdeployment health concerns of members of the armed forces, including outreach and risk communication, record keeping, research, utilization of new technologies, international cooperation and research, health surveillance, and other health-related activities;
- evaluate the health care provided to members of the armed forces both before and after their deployment on military operations;
- provide and direct training of DoD and VA health care personnel in the evaluation and treatment of postdeployment diseases and health conditions; and
- recommend to DoD and VA ways to improve health care, including improvements in the monitoring and treatment of members of the armed forces.

With different versions of the legislation in the House and the Senate, and with very different perspectives on how to approach this issue, the legislation was referred to a conference committee. Ultimately, after much discussion and negotiation, a compromise was reached that authorized the VA to contract with the National Academy of Sciences.

In September 1998, President Clinton signed Public Law 105-368, the Veterans Program Enhancement Act of 1998. Section 103 of that legislation directed the Secretary of Veterans Affairs to enter into an agreement with the National Academy of Sciences to help develop a plan for establishing a national center (or centers) for the study of war-related illnesses and postdeployment health issues (Appendix B). As stated in the legislation, the purposes of such centers might include: carrying out and promoting research regarding the etiologies, diagnosis, treatment, and prevention of war-related illnesses and postdeployment health issues; and promoting the development of appropriate record keeping, risk communication, and use of new technologies.

Additionally, the Act authorized the Academy to make recommendations regarding (a) design of an organizational structure or structures, operational scope, staffing and resource needs, establishment of appropriate databases, the advantages of single or multiple sites, mechanisms for implementing recommendations on policy, and relationship to academic or scientific entities, (b) the role or roles that relevant Federal departments and agencies should have in the

establishment and operation of any such center or centers, and (c) such other matters as it considers appropriate.

The Academy was directed to report on its recommendations to the secretaries of Veterans Affairs, Defense, and Health and Human Services, and to the Committees on Veterans' Affairs of the Senate and House of Representatives, not later than one year after the date of the enactment of this Act.

MILITARY AND VETERANS HEALTH COORDINATING BOARD

In 1998, the Executive Office of the President issued a Presidential Review Directive that emphasized the need for a coordinated program of research that could include "deployment health related research, population-based troop health assessments before, during, and after deployments, and epidemiological research to determine whether deployment-related exposures are associated with post-deployment health problems" (Executive Office of the President, 1998, p. 53).

A major recommendation of the directive was the creation of a Military and Veterans Health Coordinating Board (MVHCB), which would provide ongoing coordination of all agencies involved in maintaining the health of military members, veterans, and their families. According to the directive, "The MVHCB would make information available as needed to other Executive Branch agencies, the Congress, the medical and scientific community, and the public. It is critical to the success of the Board that it adopts an inclusive mode of operation" (Executive Office of the President, 1998, p. 50).

Members of the MVHCB are the secretaries of Veterans Affairs, Defense, and Health and Human Services. The work of the Board is to be carried out through three working groups that address issues related to deployment health, research, and health-risk communication (MVHCB, 1999). Working group membership will be comprised of representatives of the respective departments.

The Deployment Health Working Group (DHWG) is charged with monitoring and coordinating interagency activities related to health protection and joint medical surveillance programs of the DoD. It will monitor contingency and deployment health planning of the armed forces and, with guidance from military and civilian health care and health research communities, make recommendations designed to enhance force health protection and medical surveillance. The DHWG also is charged with making recommendations to the relevant agencies on their preparations for postdeployment health evaluation and health care needs of military members, veterans, deployed civilians, and their families. The DHWG conducts an ongoing review of compliance with the recommendations of external review bodies and provides recommendations to the Board to ensure that "lessons learned" from combat and other military deployments and research findings are translated into effective preparation for future operations (MVHCB, 1999).

The second working group of the Board is the Research Working Group. The RWG will provide recommendations and coordination for research activities on deployment health issues affecting military members, veterans, deployed

civilians, and their families. This group will coordinate deployment health-related research studies and, to prevent unnecessary duplication and assure that resources are directed toward high-priority studies, it will be the forum for information exchange within the research community at large and for research coordination among the three participating departments. The RWG is charged with encouraging independent, scientific peer review of research in all its activities. This group assesses the state and direction of research on deployment and postdeployment health issues, identifies gaps in knowledge and understanding of issues relevant to service member and veteran health, proposes testable hypotheses, recommends research directions for participating agencies, reviews research concepts as they are developed, and collects and disseminates information on scientifically peer-reviewed research. The RWG also makes recommendations concerning appropriate responses and actions to research findings and maintains an ongoing review of the status of compliance with recommendations of external review bodies regarding research.

The third working group of the Board is the Health Risk Communication Working Group which will provide recommendations and coordination for the health-risk communication efforts of the DoD, VA, and HHS for military members, veterans, deployed civilians, and their families. This group coordinates interagency advice to the DoD on health-risk communication strategies and research and coordinates interagency activities to provide health care providers with up-to-date guidance on health-risk communication about deployment and battlefield health risks, preventive measures, and treatments.

The MVHCB is staffed by representatives of the DoD, VA, and HHS as designated by the members of the Board or their principal alternates. An executive director is appointed by the VA Board representative after concurrence from DoD and HHS. For administrative purposes, the executive director reports to the VA's Under Secretary for Health. Additionally, each department provides appropriate staff to ensure the efficient and effective functioning of the Board. At a minimum, the Board staff includes an executive director, three staff officers (in the areas of military public health, health science, and health-risk communication), and an administrator/program analyst.

THE VIEWS OF VETERANS

Veterans' organizations were instrumental in developing the idea for a national center for the study of war-related illness and postdeployment health issues, and these organizations continue to support the national center concept. Representatives of three veterans' organizations attended the committee's March 1999 workshop to present their organizations' perspectives.

William Brew testified for the Paralyzed Veterans of America (PVA), emphasizing the need to adopt a broad definition of the term "war-related illness" that encompasses the prevention and treatment of traumatic injuries. Additionally, the PVA takes the position that the center should be run by an entity inde-

pendent of the VA or DoD, because of a general distrust by many veterans of the way that the VA and DoD handled prior military health issues, including the use of herbicides in Vietnam. The VA's role in the compensation of veterans also is problematic, since there is at least a perceived conflict between the role of the VA as researcher into war-related illnesses and its role as payor of disability benefits for veterans found to have war-related illnesses. Mr. Brew also emphasized the importance of including guard and reserve units when studying such illnesses.

The American Legion, represented by Matthew Puglisi, emphasized the need for multiple national centers that focus on prevention strategies, risk communication, and treatment of war-related health concerns. According to the Legion, it is important that veterans and their families, legislators, and the general public have reliable information to make informed decisions. Characteristics of a national center could include:

- a multicenter approach (jointly sponsored by VA, DoD, and HHS) with at least one center located at a military hospital;
- independent oversight of any VA administration of the centers;
- an oversight coordinating board with a representative from the Joint Chiefs of Staff;
- a long-term commitment to the center(s); and
- an occupational health approach that focuses on the unique workplace issues of concern.

Paul Sullivan of the Gulf War Resource Center advocated the need for the national center to be as independent of the VA and DoD as possible. Issues of concern to Gulf War veterans include delayed responses by the VA and DoD in addressing potential exposures to hazardous chemicals and other substances, as well as such data issues as the need in future deployments for collecting more thorough exposure data.

NATIONAL RESEARCH CENTERS

Department of Defense Centers for Deployment Health

In early 1999, the Defense Authorization Bill for fiscal year 1999 (Public Law 105-261) was passed, authorizing the Secretary of Defense to establish a center devoted to ". . . longitudinal study to evaluate data on the health conditions of members of the Armed Forces upon their return from deployment on military operations for purposes of ensuring the rapid identification of any trends in diseases, illnesses, or injuries among such members as a result of such operations." In response, the DoD Assistant Secretary of Defense for Health Affairs directed the service branches to establish and fund the Centers for Deployment Health.

These centers include: (a) a clinical center at Walter Reed Army Medical Center; (b) a research center at the Naval Health Research Center in San Diego; and (c) a surveillance center at the Army Center for Health Promotion and Preventive Medicine (CHPPM). The decision was made to use three centers in order to take advantage of existing operational capabilities, and to coordinate such efforts within the DoD and across agencies through the Military and Veterans Health Coordinating Board. The mission of the proposed centers is to:

- manage the Comprehensive Clinical Evaluation Program and the Specialized Care Program with related quality improvement, service evaluation, and continuing medical education efforts;
- conduct clinical research evaluating risk factors, etiologies, new treatments, and prevention strategies targeting deployment health concerns;
- develop risk-communication interventions and evaluations;
- conduct surveillance for patterns and risk factors for illnesses, injuries, and symptoms;
- plan, coordinate, and conduct epidemiological analysis of medical surveillance data relevant to specific deployments;
- conduct epidemiological studies investigating the longitudinal health experience of previously deployed military personnel, and develop and evaluate health surveillance strategies; and
- conduct longitudinal studies of health outcomes, including studies of reproductive outcomes, involving both personnel on active duty and those who have left military service.

Deployment Health Clinical Center

The first of the three centers identified by the DoD is the Deployment Health Clinical Center, located at Walter Reed Army Medical Center and built upon the work of the Gulf War Health Center. Funding for this center will be managed through the Department of the Army. The goals of this center are to:

- maintain and improve primary and tertiary health care for individuals with deployment-related health concerns;
- maintain, improve, and explore the use of health information systems to improve the continuum of deployment-related health care that the military offers and to improve military medicine's capacity for identifying emerging deployment-related illnesses;
- develop a program of military-relevant clinical research, including multicenter controlled clinical trials, risk-communication strategies, and clinical health services research;
- develop, implement, and sustain an evidence-based military medical education program to increase the volume, quality, rate, and ease of use of clinically

relevant research knowledge disseminated to military health care providers regarding deployment-related health care and communication strategies.

The center's system of care will involve population- and care-based communication approaches and innovative primary and specialty care treatment of symptoms and concerns. It is intended that this be accomplished through development of an evidence-based medicine model and specific ways to disseminate that model to both providers and military personnel. Additionally, the center plans to develop a clinical research program that will evaluate postdeployment concerns and needs of military personnel, as well as how effectively those needs are met. Research foci would include health services research, multicenter trials, and development of guidelines for care of individuals after they have been deployed.

Deployment Health Research Center

The Naval Health Research Center in San Diego has been designated the DoD Deployment Health Research Center. Funding for this center is provided by the DoD Director of Defense Research and Engineering through the Army Medical Research and Materiel Command. The goals of this center are to:

- manage epidemiological studies investigating the longitudinal health experience of previously deployed military personnel, and develop and evaluate appropriate health surveillance strategies; and
- develop a research portfolio of studies of symptoms, hospitalizations, reproductive outcomes, mortality, and other health outcomes for all DoD beneficiaries, including those on active duty as well as retirees, and dependents.

Research activities for this center are part of a larger program effort of epidemiological assessments that includes HIV studies, occupational epidemiology, and global surveillance for emerging infections, as well as research on health-behavior interventions for the prevention of musculoskeletal injuries, alcohol misuse, and sexually transmitted diseases/HIV.

While some of the work of this center overlaps with that of the other two components of the DoD Centers for Deployment Health, the health research center will focus on hypothesis testing, the application of scientific methods to particular issues (e.g., epidemiological methods), and the dissemination (journal publication) of results and findings of studies. The main requirement of all studies conducted in this center is that they be controlled epidemiological studies. Such studies will be collaborative within the armed services (Navy, Air Force, and Army), with other federal agencies, and with universities.

In the future, key factors in the conduct of deployment health research will include sites of future deployments, immunizations used, need for stored biological samples and improved exposure information, the development of out-

come measures, and the ability for improved information linkage with the goal of identifying causes and preventing future episodes of postdeployment health problems.

Deployment Health Medical Surveillance Center

The major repository for data on military personnel is the Directorate of Epidemiology and Disease Surveillance of the Army Center for Health Promotion and Preventive Medicine. CHPPM has been designated as the DoD repository for all theater medical surveillance and treatment data collected by the armed services, the Unified and Specified Commands, and the individual commands within the services.

The Directorate has two major sections, the Epidemiology Division and the Army Medical Surveillance Activity (AMSA). AMSA maintains (a) the Defense Medical Surveillance System (DMSS), (b) the DoD serum repository, (c) the Defense Medical Epidemiology Database (DMED), and (d) the Medical Surveillance Analysis Contract.

DMSS will be designated as the DoD Deployment Health Medical Surveillance Center. The information contained in the DMSS ranges from preinduction data (including initial HIV tests, and limited medical information from the military entrance processing station) to postdischarge data. Ultimately, databases for assignments and deployments, inpatient hospitalizations, ambulatory data, reportable diseases, health risk assessments, and pre- and post-deployment specimens and surveys will be linked through the DMSS.

The Defense Medical Epidemiology Database 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, and reportable disease and deployment information.

Currently, reportable disease data are being collected independently by each service, but the DoD is working to implement a triservice (Army, Navy, and Air Force) reportable-disease database. Health risk assessment has been an Army-only system that includes such behavioral factors as smoking, alcohol use, seatbelt use, and exercise. It eventually will be superseded by the Health Enrollment Assessment Review developed by the Air Force.

Environmental exposure information currently is not 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. CHPPM has been designated as the repository for all theater medical surveillance and treatment data.

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

Without a DoD partner in the research effort, access to much of this information is limited. There are two working models for how such a partnership might take place. One approach is for a university to request that the DoD researchers join in a research partnership. The problem with that approach is that universities frequently do not address the operational issues that are of prime interest to the DoD. The alternative model is for the DoD to be the lead investigator and seek support from a university or other agency with needed expertise. That approach is more likely to receive funding.

Department of Veterans Affairs

Research Overview

The Department of Veterans Affairs serves an estimated 25.6 million veterans, of whom nearly 80 percent served during defined periods of armed hostilities (VA, 1999a). The VA is organized into three major divisions: the Veterans Health Administration, the Veterans Benefits Administration, and the National Cemetery System. It is the Veterans Health Administration that carries out the VA's health-related research and development activities.

Under the VA's chief research and development officer, there are four research services: medical research, health services research and development, rehabilitation research and development, and cooperative studies. Research at the VA is conducted as an intramural program, and principal investigators and center directors must have at least a 5/8 full-time equivalent appointment with the VA. The VA has developed formal affiliations with academic institutions throughout the country, and the strength and depth of these collaborations have enhanced the VA's research efforts. Research funding is awarded through a competitive peer-review process, and research is conducted at more than 100 VA medical centers nationwide. The VA focuses on research that will have clinical applications; as a result, approximately three-quarters of the principal investigators are clinician researchers.

In 1997, at the request of the VA Research Realignment Advisory Committee, the VA established the following designated research areas: acute and traumatic injury, military and environmental exposures, chronic diseases, sensory disorders and loss, mental illness, substance abuse, special underserved high-risk populations (including the homeless), aging and age-related changes, and health services and systems. The VA and DoD work collaboratively in a number of these areas, including prostate disease, emerging pathogens, military

operational stress-related illnesses, combat casualty and wound repair, and the physiological foundation of physical performance.

The VA's Environmental Epidemiology Section maintains a complement of data resources that are crucial for epidemiological research on veteran populations. Several registries have been developed (the Agent Orange, Ionizing Radiation, and Persian Gulf registries) that contain data on many veterans from specific conflicts or with specific exposures. Patient treatment files contain online patient discharge records for patients treated in VA health care facilities and can be used for hospitalization and case-control studies. The Beneficiary Identification and Record Locator Subsystem has approximately 40 million online records on veterans and dependents who have filed VA claims. This database can be used to track individuals for vital status; it also has death certificate information. Additionally, in order to locate individuals and process claims, the VA has access to the Social Security Administration's Death Master File and the Internal Revenue Service's Taxpayer Address File through interagency agreements. Records on retired military personnel are available through the National Personnel Records Center.

In 1990, the VA and DoD entered into an agreement to transfer directly to the VA the medical records of individuals separating from the military. The nature and extent of the data resources available through the VA make them valuable resources for epidemiological research on veteran populations. The complexity of the databases and concerns about preserving data privacy, however, have significant implications on how non-VA researchers can utilize this information.

VA Centers

In conjunction with its investigator-initiated research, the VA conducts research through a number of designated centers. The Medical Research Service funds research centers focusing on schizophrenia, AIDS, alcoholism, and diabetes. Additionally, four environmental hazard centers were established in 1994 to focus on health concerns of Gulf War veterans. The Rehabilitation Research and Development Service addresses the minimization of disability and restoration of function in veterans disabled by trauma or disease and funds six centers of excellence that focus on geriatric rehabilitation; functional electrical stimulation; healthy aging with disabilities; mobility; auditory research; and amputation, prosthetics, and limb loss prevention. Through the Health Services Research and Development Service, 11 Centers of Excellence are funded to address a wide variety of issues related to improving health services, including quality of care and primary care delivery. The VA's Cooperative Studies Program facilitates the use of multicenter clinical intervention studies and funds four coordinating centers and three epidemiology research and information centers.

The following examples provide information on potential models for a national center (or centers) on war-related illness and postdeployment health issues situated within the VA system.

Geriatric Research, Education, and Clinical Centers. The Geriatric Research, Education, and Clinical Centers were implemented by the VA in 1975 to address health care issues for the aging veteran population. The focus of the GRECC program is on enhancing research, education, and clinical care by integrating the three elements in each center. There are currently 18 GRECCs located throughout the country, with each center focusing on a specific research area in geriatrics or gerontology. A competitive peer-reviewed proposal process is conducted to select the centers. Priority areas in aging research that are not currently being sufficiently addressed are identified by the GRECC program; however, VA facilities have an open competition for research topics, and five pilot research projects may be submitted as part of the proposal.

Based on a core staffing model of 12 full-time-equivalent employees, the staff of each GRECC includes a director, three associate directors (research, education and evaluation, and clinical), five researchers, and three administrative support staff (Goodwin and Morley, 1994). All GRECCs are required to have close affiliations with medical and other health professional schools, and the centers have developed extensive fellowship training, professional health care training, and continuing education programs. GRECCs receive significant non-VA funding, primarily from the National Institutes of Health. From 1981 to 1991, funding from non-VA sources grew from 48 percent to 79 percent of the GRECCs' total research funding (Goodwin and Cohen, 1994).

A critical component of the success of the GRECC program has been independent evaluation. In 1980, Public Law 96-330 authorized the establishment of the Geriatric and Gerontology Advisory Committee, a committee of non-VA experts. The committee conducts site visits of each GRECC in three-year cycles, and its findings are presented to VA officials and Congress. Additional evaluation components include specific performance measures that were implemented in 1997.

National Center for Post-Traumatic Stress Disorder. Another model for a national center program operating within the VA is the National Center for Post-Traumatic Stress Disorder. Established in 1989 as a result of congressional mandate (Public Law 98-528), the center promotes research, education, and training on the causes, diagnosis, and treatment of PTSD and other stress-related disorders. The center is structured as a multisite consortium that unites existing VA centers, each with an area of unique but complementary expertise. The center's seven divisions focus on behavioral sciences (Boston, MA), education (Menlo Park, CA), women's health sciences (Boston, MA), clinical neurosciences (West Haven, CT), clinical program evaluation (West Haven, CT), cross-cultural issues (Honolulu, HI), and executive planning and information resources (White River Junction, VT). The center has developed extensive training programs for mental-health and

primary-care clinicians, and it works in conjunction with the academic community and with a number of other federal agencies, including DoD, the Centers for Disease Control and Prevention (CDC), the National Institute on Mental Health, and the National Institute of Justice.

The PTSD center serves as a national clearinghouse for information on the treatment, etiology, diagnosis, and prevention of PTSD. This information is available through a number of publications and venues, including newsletters, research publications and presentations, an Internet site, and the PILOTS (Published International Literature on Traumatic Stress) bibliographic database. The audience for information dissemination includes veterans and their families, VA and civilian health care providers, and the research community.

National Science Foundation Engineering Research Centers

Another potential model of a program of national centers is the National Science Foundation's (NSF) Engineering Research Centers (ERCs). In the early 1980s, the NSF recognized a need for research centers in engineering that would encourage cross-disciplinary research and improve the training that engineering students received in the practical applications of engineering for industrial uses. At NSF's request, the National Academy of Engineering examined the issue and proposed guidelines for an Engineering Research Center program (NAE, 1983). The program was begun in 1985, and there are currently 21 ERCs located throughout the country.

While the topics are quite different, there are a number of cornerstone elements of this program that may be relevant for establishing national centers on war-related illness and postdeployment health issues. These elements include:

- Focused strategic goals.
- Defined deliverables.
- Long-term funding commitments. ERCs are funded in two 5-year increments, with reviews at the 3-year and 6-year points. It is expected that they will become self-sufficient after 10 years and not receive additional NSF funds after that time.
- Peer-review and competition for center sites and for research topics, including technical review and site visits by independent expert panels.
- Emphasis on interdisciplinary research, collaboration, and flexibility.
- Oversight and performance review. There is a strong evaluation component of the entire program and of individual centers, including evaluation studies by experts outside NSF and annual reviews of centers.

VA PLANS FOR A NATIONAL CENTER ON WAR-RELATED ILLNESSES

The VA presented its proposed plans for a national center (or centers) for the study of war-related illness and postdeployment health issues to the committee (VA, 1999b). Underlying the VA's concept of a national center is the need for (1) preventive strategies to minimize illness and injury that could be implemented prior to, during, and after future conflict; and (2) increased attention to improving the care of active-duty and veteran patients. The VA views a national center as an integrated approach that would contribute to improving the health of active-duty military personnel and veterans after peacekeeping missions and war.

The four major program components of the VA's plans for a national center (or centers) focus on research, clinical care, risk communication, and education. First, it is intended that each center implement a balanced program of epidemiological, clinical, health services, and basic research. The results of such research are to be disseminated through publications, scientific presentations, training, and education programs to the medical, scientific, and veterans' communities. Second, it is proposed that the center (or centers) would integrate new and existing knowledge and skills into medical practice through the use of education and training programs for students, residents, VA staff, and the medical community.

Design, implementation, and evaluation of clinical care models for postdeployment illnesses of veterans is the third major component of the center (or centers). Demonstration projects on new approaches to clinical care might include multidisciplinary clinics, postdeployment evaluation and management units, specialized clinics and consultation teams, case management in primary care, cognitive behavior therapy, sleep evaluation programs, and rehabilitation units.

Finally, each center would be responsible for developing and coordinating effective health-risk communication programs that provide military personnel, veterans, and their families with up-to-date information about postdeployment health issues. The center (or centers) would serve as a focus for coordinating health-risk communication efforts of DoD and the VA.

The VA plans require that each center be located at a VA medical center that has strong academic affiliations with medical and other health professional schools. Additionally, it is considered crucial for the center (or centers) to actively collaborate with the DoD, particularly the Centers for Deployment Health. Other affiliations would include HHS (particularly the Centers for Disease Control and Prevention and the National Institutes of Health) through memoranda of understanding and other mechanisms.

Center sites would be chosen through a competitive peer-reviewed selection process. Program evaluation and oversight of the selection process and center productivity would be conducted by a non-VA advisory committee composed of veterans, health care providers, and scientists. Centers would report to a central

VA program office that would coordinate the federal/academic collaborations, oversee the funding process, and work closely with the Military and Veterans Health Coordinating Board and the advisory committee.

The background information discussed in this chapter was useful to the committee as it deliberated on its findings (Chapter 3) and then went on to fully develop its recommendations for a National Center (Chapter 4).

3

Findings

In preparing to assist in developing a plan for establishing a national center (or centers) for the study of war-related illnesses and postdeployment health issues, the committee reviewed and analyzed the background information received. From this analysis emerged a number of findings that guided the committee in developing its recommendations.

• Extensive research exists on the health of veterans of military conflict.

Both the DoD and VA have spent millions of dollars on research related to military deployment. A rich literature exists on the adverse health effects of military conflicts, including World War II, Korea, and Vietnam. Most recently, the DoD and VA have funded more than 120 distinct research projects on Gulf War veterans' illnesses, focusing on such topics as prevalence of and risk factors for symptoms and alterations in general health status, brain and nervous system function, reproductive health, immune function, mortality, environmental toxicology, chemical weapons, depleted uranium, pyridostigmine bromide, leishmaniasis, interactions of exposures, and prevention of diseases and illnesses (Research Working Group, 1998).

• The definition of deployment-related health issues selected for research has been too narrowly focused and has excluded some health consequences related to deployment.

The definition of war-related illnesses and postdeployment health issues must include a broad construct. Most current research, however, is limited to the

traditional considerations of such things as acute illnesses and injuries resulting from combat, training, infectious diseases, and environmental exposures. Issues that fall within the construct of deployment health research should include: diagnosable conditions; medically unexplained symptoms (both physical and mental); effects on health-related quality of life (e.g., death and duration of life, impairment, physical and mental functional status, health perceptions, and opportunity [the capacity for health, the ability to withstand stress, and physiologic reserves]); family impacts; and sequelae of combat injuries. Such issues may arise prior to, during, or following deployment. The focus of research efforts, then, should encompass this broadened definition of deployment health.

• There are gaps in the emerging data relevant to the study of war-related illnesses and postdeployment health issues.

Data generated by the DoD primarily relate to active-duty soldiers. Information regarding their health tends to focus on acute effects of war-related illnesses. Many deployed personnel in today's military, however, may be activated from reserve units that are deployed, then separated soon after return from conflict. The VA, on the other hand, concentrates on the health of those individuals no longer on active duty, and this frequently includes older veterans. There are significant gaps in knowledge, both in the focus of research by the DoD and VA as well as in the delivery of services from postdeployment to later in life.

• Many investigations of health issues and effects of deployment have been mounted in response to health problems after they occurred, rather than being undertaken proactively.

A review of previous research led the committee to conclude that research has been aimed at attempting to solve identified problems, such as the health effects of mustard gas in WWII testing, and of Agent Orange in Vietnam, as well as the medically unexplained health problems of individuals deployed to the Gulf War. Such research efforts increased as complaints from the veterans' community, the Congress, and the general public increased, yet research still lagged far behind efforts to provide care. Research efforts only recently have begun to focus on a broader, more proactive research agenda.

The committee was impressed with the newly broadened focus of research into war-related illnesses and postdeployment health issues. As with all research, the quality of the studies varies. Many excellent efforts have been fielded and the findings reported in prestigious biomedical journals. These research efforts have in large part, however, not been undertaken in response to a well-developed and coordinated research agenda. Further, coordination of research efforts and strategies, as well as communication of findings, has been limited.

• Many veterans and some congressional staff are skeptical of the objectivity of both the DoD and VA in the conduct of research into deployment-related health issues.

Veterans have emphasized the perceived lack of credibility of both these agencies, despite the tremendous research and treatment efforts they have undertaken. One reason for this credibility gap may be the previous actions of DoD and VA in addressing military health issues of prior conflicts, such as health effects of herbicides in Vietnam. Additionally, the VA is perceived as having a conflict of interest between its role as payor of disability benefits for veterans found to have war-related illnesses and its role as researcher into war-related illnesses. Distrust of the DoD was exacerbated when it notified 100,000 veterans of the Gulf War that they may have been exposed to chemical warfare agents destroyed at Khamisiyah, after the department had made repeated assurances that no such exposures had occurred.

Concerns such as these encouraged the committee to structure a national center, such that oversight of its efforts would include representatives of the VA and DoD, while ensuring that the center would be as independent as possible from direct control by these agencies.

• None of the locations of existing or proposed centers provides an adequate model for a national center that not only must be responsible for the conduct of a broad range of research but also must provide for synthesis and coordination of existing research efforts and for proposing policy changes based on research findings.

Models of a national center or centers were discussed in Chapter 2. Additionally, the committee considered the possibility of placing a national center in the National Institutes of Health, in the Centers for Disease Control and Prevention, or within a university setting. Advantages and disadvantages of these settings were analyzed, and the strengths and limitations of each are displayed in Table 3.1 below. The committee also considered dividing the center between two federal departments (e.g., DoD and VA) but determined that this option would not fulfill the goals of a national center. Further elaboration of this analysis appears in Chapter 4.

• Examples exist of centers that cut across agencies and groups to carry out effective research agendas.

The committee found the newly established Military and Veterans Health Coordinating Board the best option for consideration as a site for the conduct of the tasks that might be envisioned for a national center (or centers) for the study of war-related illnesses and postdeployment health issues.

This chapter has described the major findings of the committee. It is with these findings in mind that the committee began to develop its recommendations for establishing a national center for research on military deployment-related health issues. The following chapter presents the committee's recommendations.

TABLE 3.1 Strengths and Limitations of Alternative Locations for a National Center for Military Deployment Health Research

Location	Strengths	Limitations
Department of Defense	• Existing infrastructure • Research expertise • Resources	• Focus on the standing military forces (active duty and reserves) • Credibility with veterans
Department of Veterans Affairs	• Existing infrastructure • Research expertise • Resources	• Focus on veterans • Credibility with veterans
National Institutes of Health	• Research expertise • Peer review system	• Different mission • No appropriate existing institute
Centers for Disease Control and Prevention	• Occupational health, prevention, and surveillance expertise • Dissemination of health information	• Different mission • Limited basic research infrastructure • Isolated from treatment and surveillance options for populations of interest
Universities	• Credibility, independence of research • Research expertise • Collaboration of multiple disciplines	• Lack of ability to coordinate federal activities • Isolated from treatment and prevention options for populations of interest
MVHCB	• Cross-departmental • Incorporate research expertise of federal and private sectors • Mission focused on deployment health	

4

Recommendations

The committee conducted its deliberations with an acknowledgement of changes in the nature and breadth of deployment efforts, as well as with awareness of the increasing interest and concern about the health of military personnel and veterans. Contemporary military strategies call for a shift from a large standing force with forward-located bases to one comprised of smaller expeditionary forces. Such forces maintain a high level of military readiness when the need arises for low- to medium-conflict or for peacekeeping and humanitarian missions. The changing nature of warfare places a greater reliance on readily deployable forces, including an increased participation by guard and reserve members. Disruption in the lives of these members is particularly turbulent in that they are drawn from civilian communities where they must leave their jobs, families, and other commitments, and that they do not always have access to the support and resources available within a military community.

Active-duty, guard, and reserve forces experience profound life disruptions through the predeployment, deployment, and postdeployment phases, and these disruptions, despite the relatively rapid and short-term experience, may have long-standing emotional and social consequences. Additionally, there is a component of deployed civilian workers who are similarly impacted by military deployment. Research is needed to better understand the impact of deployment experiences on the well-being of individual service members, as well as on their families, and to inform policy regarding the social and organizational responsiveness to these significant life disruptions. These issues span the purview of federal departments and have a breadth that encompasses biomedical and social sciences research.

Committee recommendations were developed with these factors in mind. The recommendations are intended to maximize productivity of current resources and efforts; encourage interdepartmental coordination at the federal

level; encompass the deployment-related health concerns of all interested parties, including veterans, active-duty personnel, guard and reserve forces, deployed civilians, and their families; and foster relevant interdisciplinary research in the biomedical, epidemiological, and social sciences. To the extent possible, committee recommendations incorporate existing efforts, structures, and plans, while striving to provide a model that will enhance trust in the scientific integrity of research results.

ASSESSMENT OF THE VA PROPOSAL

The committee analyzed the VA's proposal to establish Centers for the Study of War-Related Illnesses and Postdeployment Health Issues. As described in Chapter 2, this proposal calls for establishing centers that have four distinct program components (research, treatment, education, and risk communication) and that are similar in structure to the VA's Geriatric Research, Education, and Clinical Centers. Such an approach has proven quite successful in the areas of geriatrics and gerontology, and the committee believes that comparable centers focused on deployment-related health also will contribute greatly to the nation's knowledge and ability to care for military veterans.

The committee, therefore, strongly supports the emulation of the GRECC program as it has been successful in training health professionals, conducting cutting-edge research in the field, and implementing effective treatment programs. Strengths of the GRECC program include close collaboration with medical schools and universities, as well as the establishment of multiple centers (each drawing on the research expertise of the host VA medical center and integrating a variety of scientific disciplines).

Further, the GRECC program has an active advisory committee, the Geriatrics and Gerontology Advisory Committee, which is composed of experts from outside the VA and is charged with evaluating the centers and providing scientific expertise on all aspects of caring for aging veterans (Goodwin and Cohen, 1994). The committee encourages the implementation of each of these features to help ensure the success and effectiveness of the VA's work on deployment-related health concerns. Further, the committee urges the VA to incorporate university-based research in its centers in order to expand the research base and foster new approaches and initiatives. VA centers structured in such a manner would play a major role in the broader National Center effort described in the following section. Therefore, **the committee recommends that the Department of Veterans Affairs proceed with its proposal to establish centers for the study of war-related illnesses, and that these centers be similar in structure to the Geriatric Research, Education, and Clinical Centers.**

ESTABLISHING A NATIONAL CENTER

A deployment-related health research agenda must be broad if it is to improve the health of deployed personnel and minimize adverse health impacts of future deployments. It will require the creativity and scientific ingenuity of researchers from multiple disciplines and varied research settings to address the wide range of health issues related to military deployments. Additionally, the changing nature of military deployment necessitates the inclusion of research that encompasses the health concerns of all deployed populations, including veterans as well as active-duty, guard, and reserve forces.

There is a tremendous amount of deployment-related health research currently underway both within the federal government and in the academic community. As described earlier, the DoD already has established its Centers for Deployment Health. Since the end of the Gulf War, more than 120 research projects on Gulf War veterans' health have been funded by the VA, DoD, and HHS. Such research is being carried out in universities, at federal research centers, and by private investigators in a variety of locations. Research on the health effects of other specific conflicts (World War II, Korea, Vietnam) has been ongoing and is anticipated to continue.

The committee concluded that the contributions of such deployment-related health research efforts would be enhanced if a mechanism were developed to integrate, coordinate, and synthesize the research. Further, an overarching research agenda is needed to identify gaps in current research, assure that missing but required research efforts are undertaken, and focus the infusion of new research funding. The committee determined that a new National Center for Military Deployment Health Research should be established to accomplish the following goals:

- facilitate a coordinated research program through development of a research agenda;
- identify research gaps and commission research to fill those gaps;
- monitor the conduct of research; and
- develop policy recommendations resulting from research.

Therefore, **the committee recommends that Congress establish a National Center for Military Deployment Health Research that will focus on the health of active, reserve, and guard forces, and veterans and their families.**

SCOPE AND FOCUS

The committee assessed the potential scope of the National Center and determined that the terms "war-related illnesses and postdeployment health issues" are encompassed by the broader concept of "deployment-related health." The traditional consideration of these issues focuses on the injuries and illnesses re-

sulting from combat, training, infectious diseases, and environmental exposures. However, the very nature of deployment involves disruption of everyday life, and the committee encompasses in its definition of deployment-related health the numerous impacts on service members and their families during the deployment, upon return home, and when reintegrating into society. Further, issues may be considered that address concerns revolving around the time prior to deployment, when individuals and families are preparing for deployment and often are uncertain about the timing and nature of the deployment. Therefore, **the committee recommends that the Center encompass a broad research agenda that addresses conditions that emerge both during and following deployment, including:**

- **diagnosable conditions;**
- **medically unexplained symptoms (both physical and mental);**
- **effects on health-related quality of life, (e.g., death and duration of life, impairment, physical and mental functional status, health perceptions, and opportunity [the capacity for health, the ability to withstand stress, and physiologic reserves]);**
- **family impacts; and**
- **sequelae of combat injuries.**

In order to address adequately all aspects of these conditions, it will be necessary for the Center to encompass diverse types of research, including epidemiological, clinical, basic biomedical, health services, social and behavioral, ethical, and risk-communication research. The committee acknowledges the breadth of the research challenge, but feels that the Center's proposed structure can encompass relevant research. To date, efforts have had to be more narrowly focused because of the missions of the individual federal departments (e.g., the emphasis on postdeployment issues by the VA because of its mission to serve veterans). A coordinated National Center program will broaden the perspective and facilitate a more coordinated approach to addressing deployment health concerns.

ORGANIZATIONAL PLACEMENT

In considering how to most effectively implement the National Center, the committee considered a variety of ways that the Center might be placed within the federal government or the private sector. The following general guidelines, based on committee findings, guided committee discussion. The location of the Center should:

- facilitate coordination;
- ensure credibility with all relevant agencies and constituencies; and
- span the breadth of applicable research.

For each of the options considered, the committee delineated the strengths and limitations while emphasizing the important role for each of the organizations in carrying out the mandate of the National Center.

Department of Defense

As discussed in Chapter 2, the DoD has implemented a deployment health program using three centers and has an extensive array of research under way. The advantages to placing the National Center within the DoD would include an existing infrastructure, extensive research expertise, and the willingness to commit resources to address the research issues. However, several concerns limit this approach. The focus of DoD's health-related mission is to address the health of active-duty personnel. Although the DoD does conduct a range of health-promotion, disease-prevention, treatment, and rehabilitation research, its mission is narrower in focus than that envisioned for the National Center. The Center's broader focus would span active-duty, guard, and reserve forces, and veteran and deployed civilian populations. Additionally, as discussed previously, the DoD lacks credibility with the veteran community.

The committee believes that the DoD must, however, play an integral role in the National Center. As discussed below, the DoD research centers on deployment health are vital components of the military deployment health research network. The committee commends the DoD's initiative in establishing these centers and encourages the DoD to continue to expand the breadth of its research efforts to encompass guard and reserve forces.

Department of Veterans Affairs

The committee concluded that there are similar strengths and limitations to locating the National Center wholly within the VA. The VA has strong research on deployment health issues. Further, as evidenced by its recent plans for Centers for the Study of War-Related Illness, the VA has the commitment and willingness to address these issues, and it has much of the research expertise needed to carry out this work. Additionally, the DoD and VA have collaborated on recent studies, particularly those related to the health of Gulf War veterans. However, the VA's mission focuses on veterans' health and does not address the active-duty component that is fundamental to the nature of the National Center. Further, there are credibility issues that again would limit the VA in serving as the locus for the National Center. The committee considered the possibility of dividing the Center between two federal departments (e.g., DoD and VA) but felt that this would not be the best option. In addition to the credibility issues, the mission of the Center requires that the Center fund research comparing the health of deployed forces with the general population, and a broader-based location for the Center with access to general population research is optimal.

The VA does have an integral role in the National Center, however. As discussed above, the committee endorses the VA's plans for Centers for the Study of War-Related Illnesses and believes that these centers will be vital to the research network on deployment health. The committee encourages the VA to move forward with implementing these centers but does not believe that these centers can carry out the functions of a National Center.

National Institutes of Health

The committee considered the feasibility of locating the National Center within the National Institutes of Health, because of its biomedical research expertise and its sterling reputation regarding research on health issues. The NIH is acknowledged worldwide for the impressive breadth and quality of its basic biomedical research. Further, NIH has an extensive infrastructure in place for its highly respected, scientific merit, peer-review of research grants and contracts. However, each of the 25 institutes and offices within NIH has a specific mission that focuses on a particular organ or organ system (e.g., National Eye Institute), population (e.g., the National Institute on Aging), or health issue (e.g., National Institute of Environmental Health Sciences). Although many of the NIH institutes are conducting research that is relevant to military deployment health, no single institute has the comprehensive breadth of mission needed for the National Center. The option of adding another institute or office that would focus on military deployment health was considered but rejected. The committee recognized that this option would require considerable resources for infrastructure and yet would still not accomplish one of the goals of a National Center—to coordinate research efforts across federal departments.

The committee does consider NIH an integral part of its plan for a National Center. NIH research that is relevant to military deployment health should be included in the Center's overarching research agenda. Additionally, as will be discussed below, the NIH peer-review process for research grants and contracts could be utilized by the National Center.

Centers for Disease Control and Prevention

In considering the placement of the National Center within the Centers for Disease Control and Prevention, the committee acknowledged CDC's strengths in a number of relevant areas, including occupational health research, prevention efforts, and health surveillance. Additionally, CDC continues to excel in dissemination of health information. CDC has worked extensively and successfully with the DoD and VA on research related to the health of Gulf War veterans. However, the goals and mission of the National Center are not central to the mission of CDC, and it would be difficult for CDC to coordinate research efforts

across the federal government. Further, CDC's mission does not include the basic biomedical research that is a necessary component of the National Center. CDC also is considered an integral part of the National Center. The relevant CDC research (e.g., occupational health research) should form part of the research network on military deployment health research.

Universities

The committee considered the option of locating the National Center outside of the federal government, within a university. Advantages of such an approach include increased credibility due to the independence of the research, the ability to have a broad collaboration of disciplines from across the university, extensive research expertise, and a willingness by universities to expand their research capabilities. However, the disadvantages of being outside the federal government outweigh the advantages.

It would not be feasible for a university-based center to coordinate federal research. Additionally, data access to relevant VA and DoD databases would be problematic. Further, this approach would isolate research from the treatment and surveillance efforts in active-duty and veteran populations. As will be discussed below, the committee views university-based research as crucial to the research network of the National Center, but does not believe that the primary location of the National Center should be in a university.

Military and Veterans Health Coordinating Board

The Military and Veterans Health Coordinating Board (see Chapter 2) offers many of the advantages of the federal government agencies, with the added strength of being a cross-departmental effort. Formed in response to a Presidential Review Directive, the MVHCB enjoys high-level federal support. The Board's charter calls for it to be chaired by the secretaries of Defense, Veterans Affairs, and Health and Human Services. The MVHCB has a broader mission than would be found in any one of the federal departments and is by its nature a collaborative effort.

The draft charter for the MVHCB calls for it to have three working groups—on research, on deployment health, and on health-risk communication. Since the mission and objectives of the Research Working Group (see Chapter 2) are encompassed in the proposed National Center for Military Deployment Health Research, the committee suggests that the new Center replace the RWG, rather than duplicate its efforts (Figure 4.1). Such an approach would increase credibility because the National Center would include all of the relevant constituencies in the research agenda-setting.

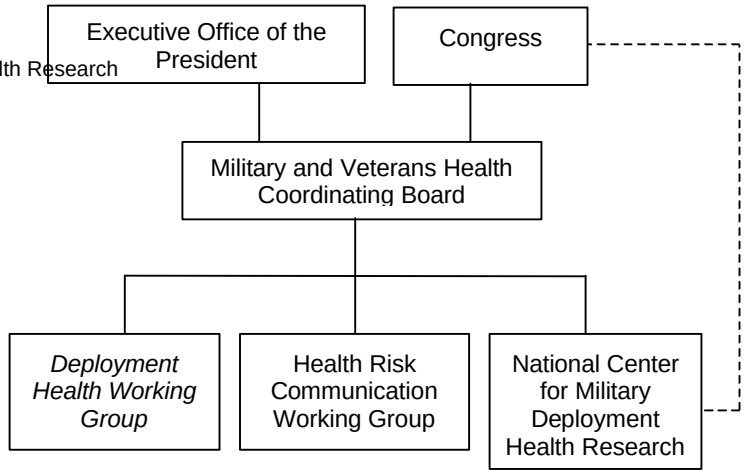

FIGURE 4.1 Organizational placement of the National Center for Military Deployment Health Research

Further, as will be described below, the National Center would have the additional responsibilities to set a research agenda, identify research gaps, and provide funding for needed research. Independence of the National Center is enhanced by the requirement that it annually report directly to Congress, as well as by the constituency of its governing body. **Therefore, the committee recommends that the National Center be placed under the auspices of and report to the Military and Veterans Health Coordinating Board. Further, the committee recommends that the National Center replace the Research Working Group of the MVHCB.**

The following section discusses the structural elements of the National Center recommended above.

STRUCTURE

The committee has designed an organizational structure for the National Center for Military Deployment Health Research that will facilitate the goals of coordinating research, identifying and filling research gaps, and developing policy recommendations resulting from research, in a way that will be deemed credible with both the research communities and the public. This structure has three key components (Figure 4.2):

• a Governing Board, composed of members of relevant constituencies, with responsibility for coordination and agenda setting, as well as for oversight of the work of the Center;

• a Research Network that integrates research efforts in DOD, VA, HHS, universities, and other sites; and

• a core of specific functions, with appropriate staff to implement such functions, under the overall direction of the Center's board and the MVHCB director.

The committee concluded that current and future resources would be used most effectively if the National Center were structured to coordinate and supplement existing research efforts of DOD, VA, and HHS, rather than to replace them. Consequently, the relevant federal departments are encouraged to continue to plan for and implement research programs perceived necessary to fulfill their missions.

One of the major benefits of the proposed structure is the participation of a broad set of constituencies, including veterans groups and the general public, on the Governing Board. This breadth of input will increase the credibility of the research process and expand the range of issues comprising deployment health as addressed by the VA, DoD, and HHS. Further, the independence of the Center is enhanced by the requirement that it report directly to Congress, in addition to reporting to the MVHCB.

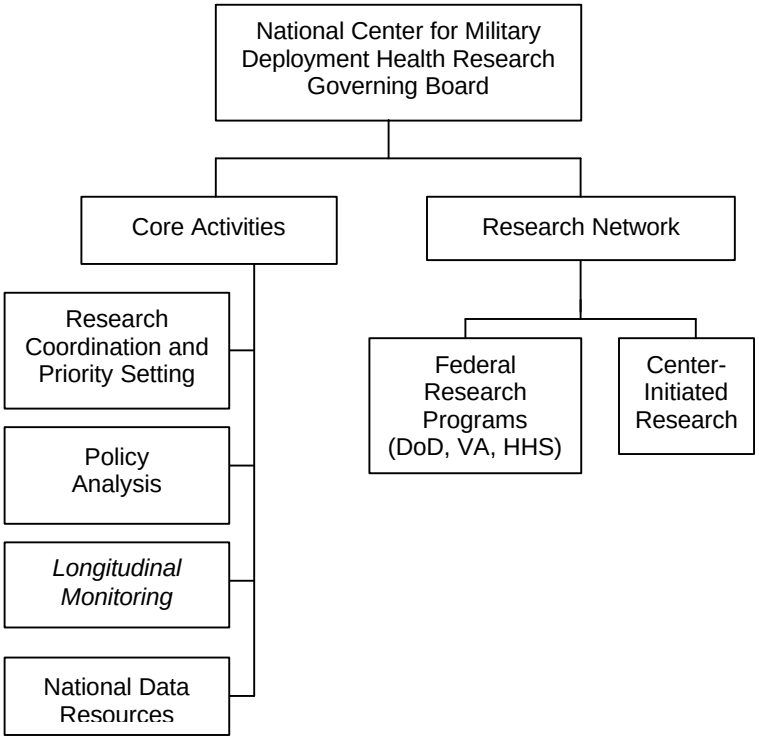

FIGURE 4.2 *Structure of the National Center for Military Deployment Health Research.*

Governing Board

Working within the structure of the MVHCB will provide the input of the federal departments. However, in order to assure the public, the Congress, the scientific community, and others that all of the Center's efforts are being conducted with the greatest degree of scientific integrity and public accountability, oversight of the Center should be by a Governing Board composed of representatives from a broad range of relevant constituencies. These constituencies include researchers, veterans and their families, the general public, and representatives of the VA, DoD, and HHS. The input of an independent scientific body should be sought in obtaining nominations for the nonfederal representatives on the Governing Board.

The research and constituency membership should be in the majority on the Board so as to ensure maximum scientific quality, broad-based decision making, and public accountability and acceptability. Therefore, the Governing Board should be composed of 21 members (three each from VA, DoD, and HHS; six from the research community; and six from the community of veterans, their families, and the public at large). The committee emphasizes the need for the researchers to represent the breadth of relevant research, including the biomedical and social sciences and ethics. As noted above, the committee encourages the involvement of CDC and NIH in the Center and hopes that these agencies will be involved through participation on the Governing Board.

Further, the committee believes it is crucial that Governing Board members serve on a rotating long-term basis, thereby allowing adequate time for them to become familiar with the complex issues and to develop a view of the evolving needs for research. Therefore, **the committee recommends that the National Center Governing Board be composed of:**

- **three representatives each from VA, DoD, and HHS;**
- **six independent representatives from the research community; and**
- **six representatives from the community at large, including veterans and their families and the general public.**

Additionally, **the committee recommends that an independent scientific entity nominate, for both the research-community and the community-at-large positions, twice the number of candidates as there are positions available.** The Military and Veterans Health Coordinating Board should select, from the list of recommended candidates, the six representatives from the research community and the six representatives from the community at large to serve on the Governing Board.

The Governing Board will serve as the steering body for the National Center, performing several critical functions. The Board will be responsible for establishing a broad research agenda encompassing the wide scope of deployment health issues, coordinating research across agencies and institutions, commissioning new research to fill in research gaps, and developing policy recommen-

dations that emerge from Center research. Further, the Board should develop policies for guiding the conduct and dissemination of center research and should develop a plan to evaluate the output and productivity of center research.

Due to the Governing Board's major responsibilities, it will need to function as a working board and divide into subcommittees to address the various tasks. Thus, it is important for the Board to have a large membership (21 members) so that each subcommittee will have representation from each of the constituencies.

The Governing Board will have reporting responsibilities to both the MVHCB and to Congress. In its annual report, the Board should provide an update on the research agenda, an overview of ongoing research activities and completed research results, and policy recommendations based on Center research. Further, the Board, as will be discussed in a subsequent section, should assess the resources necessary to carry out the work of the Center and to fill gaps in research. In its annual report, the Board should propose a Center budget.

The committee recommends that the functions of the Governing Board include:

- **development of a coordinated research agenda;**
- **commissioning of new research;**
- **creation of policies for the conduct and dissemination of Center research;**
- **evaluation of the output and productivity of Center research;**
- **development of policy recommendations that emerge from Center research;**
- **development of the Center's proposed annual budget; and**
- **preparation and transmittal to Congress of an annual report.**

Research Network

The scope of current deployment health research, along with the changing nature of deployment, were key factors in determining the need for a broad research agenda. In addition to the breadth of biomedical research that should be undertaken, a comprehensive portfolio of relevant social sciences research is needed. Further, the research agenda should include an emphasis on the health-related ethical issues that surround war and other military deployments. As the nature of conflicts and events that trigger deployment change, and as health-related decisions and issues become increasingly complex, research on the ethical implications is crucial. The Ethical, Legal, and Social Implications Program at the National Human Genome Research Institute is successful at encouraging research on ethical and social issues and provides examples of the ways in which research on the ethics of deployment-related health issues could be fostered.

Since there is a great deal of ongoing research on deployment health issues, the committee structured the Center so as to take full advantage of current ef-

forts while ensuring a coordinated credible research agenda that addresses research gaps. Thus, there are two components to the research portfolio of the Center: federal research programs and Center-initiated research. This structure will provide minimum disruption to the ongoing research activities while adding a needed mechanism for research priority setting and coordination, for dissemination of research results, and for undertaking tasks most appropriate for a central organization. It is hoped that this structure will encourage more independent investigators (funded directly by federal agencies or through Center-initiated research) to be involved in military deployment health research and thereby stimulate the breadth and creativity of scientific inquiry.

Federal Research Programs

The committee acknowledges and commends current federal efforts to research deployment-related health issues. Current and future deployment health research by the VA, DoD, and HHS would be considered in the work plan of the Center, but the Center would not take over administrative or professional responsibility for its conduct. Rather, such research would remain the responsibility of the relevant federal agency. As part of the process to develop and coordinate a research agenda, the Center would conduct an inventory of ongoing research, and federally sponsored researchers (intramural and extramural) would be involved in developing the Center's research agenda. The committee strongly encourages the federal departments to continue their deployment health research programs and to work through the Center to facilitate coordination across the departments.

Center-Initiated Research

One of the tasks of the Center's Governing Board will be to identify gaps in current research. The committee believes that the Center should accept operational responsibility for commissioning, funding, and overseeing a program of Center-initiated research that would fill the gaps in the research agenda. This research would be carried out by university or government researchers who would compete for awards to conduct the research.

The Center-initiated research program should be implemented through the announcement of a set of Requests for Applications and Requests for Proposals that would specify the nature of the needed research projects. Given its expertise and existing infrastructure for scientific merit review, the NIH Center for Scientific Review should be tasked with processing the grant and contract applications. Further, the peer-review process of the NIH should be used, to the extent possible, to assess the scientific merit of the applications and proposals. The final research funding decisions would be made by the Center's Governing Board, which would focus on the programmatic considerations of whether proposals receiving a high

scientific rating would further the research agenda of the Center. Therefore, **the committee recommends a broad-based Center-initiated research program that would solicit proposals from federal agencies, universities, and other research sites and that would be managed by the National Center.**

Goals of the Research Network

It is the committee's hope that establishing a network of research sites with an overarching research agenda will bolster ongoing activities, foster creativity for new projects, encourage the use of established peer-review mechanisms for evaluating and funding intramural and extramural research, and promote wide dissemination of research results. Further, it is important for the research network to encompass interdisciplinary work in the biomedical and social sciences, including ethics. Such research should not be limited to academic medical centers but should be expanded to encompass relevant university-wide research resources.

The committee concluded that each of the federal departments should expand its funding of university-based research on deployment-related health in order to widen the base of researchers involved in this field. HHS is encouraged to focus specific extramural NIH funding on these issues. One of the benefits of promoting university-based research is, of course, the enhancement of educational programs to provide the next cohort of medical and social science researchers in this area.

The committee strongly urges that all Center-initiated research be conducted using a core set of principles:

- utilization of a scientific peer-review process for all research;
- dissemination of research results to the scientific community through conventional scientific venues of communication, including presentation at scientific conferences and publication in peer-reviewed journals; and
- encouragement of interagency, interdepartmental, and federal-academic sector collaboration, including collaborative proposals with principal investigators and colleagues from several federal departments and universities.

Center Core

To fully implement the work of the Center and to ensure coordination of efforts, the Center must carry out four core activities that will facilitate the work of researchers from across federal departments, universities, and other institutions. These key core functions are:

- research coordination and priority setting;
- research synthesis for the purpose of developing policy recommendations;

- oversight of longitudinal monitoring efforts on veterans' health; and
- facilitating the use of national data resources available for deployment health research efforts.

These activities are viewed by the committee as the intramural work of the National Center and should be carried out under the Governing Board's direction by the Center staff and with the input of all of the relevant constituencies.

Core Staff and Offices

A full complement of core staff is crucial. There should be sufficient full-time staff members to work with the Governing Board and to carry out the Center's four core activities. It is envisioned that the size of the staff will grow as the Center becomes fully implemented. As described below, the core activities of the Center will require considerable staff time and expertise. Staffing expertise needed includes health policy analysis and development, deployment-related health research, research program management, and research administration.

In keeping with the staffing structure suggested for the MVHCB, the committee suggests that the National Center be directed by a deputy director of the MVHCB who reports to the executive director of the MVHCB. The deputy director for the National Center should have the experience and seniority necessary to enhance interdepartmental coordination and should have relevant research expertise. This individual should be selected by the Governing Board and approved by the MVHCB.

The draft charter for the MVHCB calls for it to be an administratively housed unit within the Department of Veterans Affairs. Such placement also would be appropriate for the National Center. It is crucial that the Center be given central office space in order to establish the location and visibility of the Center.

Core Activities

An effective National Center must perform some central and key functions that cannot be performed by individual federal agencies or researchers because of the overarching nature of the tasks.

Research Coordination and Priority Setting. As discussed above, the Center will function to set a research agenda, establish research priorities, coordinate research efforts, and serve as an intellectual gathering exchange for researchers. Further, the Center will initiate and fund new research projects to fill the gaps in the research portfolio.

To fulfill these responsibilities, the Center should sponsor conferences and workshops to gather input for the research agenda and to bring researchers together in ways that encourage collaborative exchanges and stimulate new research

initiatives. To increase scientific input in the development of the research agenda, the Center's Governing Board may establish advisory groups or use other mechanisms to receive technical advice on each of the major areas of research.

To ensure that all aspects of the research agenda are addressed, the Governing Board and Center staff will need to determine the research gaps and initiate and fund research grants and contracts. This work may be done in collaboration with NIH as discussed above, but final funding decisions will be the responsibility of the Governing Board.

It is envisioned that the Governing Board's annual report to Congress will serve as a mechanism for outlining the research agenda, specifying the ongoing work of the federal agencies and universities, and identifying how the research gaps are being filled.

Policy Analysis. The Center's research results should be used to guide development of policies for prevention and treatment strategies aimed at mitigating potential health consequences of deployment and improving the health of those participating in such engagements. Developing policy recommendations based on research results requires the synthesis and analysis of relevant research. The expertise of the core staff and the guidance of the Governing Board should provide the expertise necessary to perform this function. The responsibility for policy recommendations related to research should remain the purview of the National Center Governing Board.

Longitudinal Monitoring. One of the current difficulties inherent in researching deployment health concerns is the lack of a system for monitoring the longitudinal health of active, reserve, and guard forces, as well as the health of veterans and their families. The VA and DoD have developed health registries for active-duty service members and for veterans involved in specific events and deployments. While these registries serve useful purposes, they reflect the health of a self-reported sample of service members and veterans, and thus they are not representative of the active-duty and veteran population in general. Of fundamental importance is the development of a longitudinal monitoring system that is representative of active-duty, guard, and reserve troops, and veterans; that measures health at specific time points; and measures changes in health over time.

The recent IOM report *Gulf War Veterans: Measuring Health* (IOM, 1999) describes a research portfolio and prospective cohort study that could, with appropriate extension, provide a model for a long-term tracking system of the health of veterans of military deployments. The portfolio encompasses three principal categories of research: population studies, health-services research, and clinical and biomedical investigations. An essential feature of the research portfolio is facilitating linkages across individual studies through the collection of a core set of key data elements (describing health, individual, and cultural characteristics) in order to provide for comparisons across all research.

It is appropriate that the research described in *Gulf War Veterans: Measuring Health* fall within the purview of the National Center. That is, the Center

could develop the RFP, review submitted proposals, provide funding, and monitor the progress of the studies. Data collected from such efforts could be incorporated into a national database on deployment-related health. The Center would not be directly involved in conducting the longitudinal monitoring, but would review the progress of its implementation.

Additionally, future efforts to measure the health of those individuals deployed to military conflicts and peacekeeping missions should include, to the extent possible, information obtained before, during, and after deployment. The National Academy of Sciences currently is conducting a study on strategies to protect the health of deployed U.S. forces, and a component of this study examines improvements in keeping medical records and documenting exposures, treatment, tracking of individuals through the medical evacuation system, and health/administrative outcomes. Data obtained before, during, and after deployment through the kinds of systems reviewed in this forthcoming Academy report will be important components of research on deployment-related health.

National Data Resources. As described in Chapter 2, there are a number of existing data resources relevant to research on deployment-related health. The DoD and VA have numerous databases that include such information as demographics, health outcomes, risk assessment, and compensation. Individual research projects also generate data that are important to future efforts aimed at understanding the health consequences of deployment.

Given the numerous and varied databases that exist, as well as the likelihood that others will be created in future efforts to study deployment-related health, a mechanism is needed to identify, inventory, and describe data sources and to analyze ways to foster their effective use. The committee believes that the National Center should perform these functions.

There are a number of issues involved in enhancing the effective use of these data sources. These issues include dealing with patient confidentiality concerns and legal stipulations on access to VA and DoD data. It is the committee's hope that as the National Center addresses data issues, one of the goals will be to develop and coordinate end-user databases that can provide relevant and privacy-protected data to Center researchers.

Therefore, **the committee recommends that the National Center be responsible for the four core activities:**

- **research coordination and priority setting;**
- **research-related policy analysis;**
- **review and analysis of longitudinal monitoring of deployment-related health; and**
- **facilitating the use of national data sources for deployment health research.**

FUNDING

The research issues faced in examining deployment-related health are complex, and it should be emphasized that a long-term commitment is needed from Congress and from the relevant federal departments in order to nurture and sustain the research efforts that will lead to productive results. Resources for the National Center will be used to fund the core activities, the Governing Board, and Center-initiated research. Funding levels for such efforts are significant.

Since this Center will involve the work of three federal departments and will require close coordination in order to ensure its success, the committee believes that the Governing Board in its annual report to Congress should recommend a proposed funding level for the Center. This proposed budget should detail the resources needed by the Governing Board and staff as they fulfill the work of the Center by carrying out its core activities and funding the Center-initiated research. National Center funding should be a line item in the budget of the MVHCB to ensure the visibility of the Center's work. Therefore, **the committee recommends that the National Center should have a clear and distinct budget for its core activities and its Center-initiated research. Further, this budget should be a line item in the budget of the MVHCB.**

SUSTAINING THE NATIONAL CENTER

Perhaps the greatest potential challenge to be faced by the National Center is sustaining its long-term presence and viability. Deployment health concerns are raised to the level of national issues only sporadically (e.g., illnesses of Gulf War veterans and Agent Orange concerns of Vietnam veterans). Given the interdepartmental responsibility of the MVHCB, the National Center could become lost in the midst of large bureaucracies. It is imperative that commitment to the Center be long-term. The committee has, therefore, developed several safeguards to help secure the Center's sustainability.

First, all relevant constituencies, particularly active, reserve, and guard forces and veterans, would be represented on the Governing Board. Additionally, it is proposed that the Governing Board report directly to Congress, in addition to reporting to the MVHCB. The establishment of a National Center has received a great deal of congressional interest and support to date, and it is hoped that continued congressional involvement will be a driving force in sustaining the Center. Further, the Center, as part of the MVHCB, would have high-level federal involvement, as it would be part of the responsibility of the secretaries of the three federal departments. Funding for the Center would have visibility because it would be a specific line item in the budget.

5

Conclusion

Conflict has been a part of human life from the earliest moments in recorded history. Although advances in technology have furthered the conduct of war, great strides in research have also been utilized to improve the treatment of those injured in war. Further, research is increasingly being focused on addressing the health effects that may result from the use of specific agents or weapons (e.g., Agent Orange in Vietnam).

More recently, attention also has begun to focus on whether there might be broader questions regarding the consequences of service in any major military engagement. And if that is so, might there be ways to prevent or at least mitigate the consequences of war-related illnesses and deployment-related health effects? Research into this aspect of the health effects of deployment and conflict has only just begun. Congress directed that the Department of Veterans Affairs contract with the National Academy of Sciences to assist in developing plans for a national center (or centers) for the study of war-related illnesses and postdeployment health issues. This report is the result of that study.

The committee has recommended the establishment of a National Center for Military Deployment Health Research, governed by an independent board composed of representatives of the scientific community, the veteran and military community, the general public, and relevant federal agencies. This Center should be situated administratively within the auspices of the Military and Veterans Health Coordinating Board and should report to Congress annually. The Center should establish a research agenda, identify gaps in existing research, commission new research to fill these gaps, review and analyze national data resources for the study of deployment-related health, and monitor the long-term health status of veterans of military deployment.

Key to the success of advances in deployment-related health is the continued research activity of the DoD, VA, and HHS, as well as the activity of the many independent researchers engaged in finding answers to the numerous remaining questions. These efforts are vital components of the research network envisioned within the National Center. The Center itself, however, must be independent of the governance of these agencies and groups in order to ensure the broadest research participation and the public perception of credibility of results.

The issues surrounding the health of the men and women who have served in war and other military operations are complex. A National Center for Military Deployment Health Research provides an opportunity to gather together the results of many individual efforts, to analyze and synthesize what this research can reveal, and to move the nation forward in ways that will help and protect those individuals who will participate in future deployments. The Center is needed to fulfill the nation's commitment to the health of veterans, active-duty military, and guard and reserve forces, and it will provide a needed impetus to improve the prevention and treatment of deployment-related health consequences.

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APPENDIX A

Workshop Agenda

INSTITUTE OF MEDICINE
NATIONAL ACADEMY OF SCIENCES

Workshop on a National Center for the Study of
War-Related Illnesses and Postdeployment Health Issues
March 18, 1999
Room 2004, Foundry Building
1055 Thomas Jefferson St., N.W.
Washington, DC

12:30–12:40 Introduction and Overview
Merwyn Greenlick, Ph.D., *Chair*

12:40–1:10 War-Related Illnesses: A Historical Perspective
Capt. Craig Hyams

1:10–1:50 Legislative Mandate for National Center(s)
Congressional Staff—House and Senate Committees on Veterans' Affairs
Ralph Ibson—House majority staff
Susan Edgerton—House minority staff
William Cahill—Senate majority staff
Kim Lipsky—Senate minority staff

1:50–3:15 Department of Defense, Centers for Deployment-Related Health
History and Overview of the DoD Approach—Lt. Col. James Riddle
Deployment Health Clinical Center—Lt. Col. Charles Engel
Deployment Health Research Center—Karl E. Friedl, Ph.D., and Dr. Frank Garland
Discussion

3:15–3:30 BREAK

3:30–5:15	Department of Veterans Affairs Proposal History and Overview—Frances Murphy, M.D. Data and Information—Han K. Kang, Ph.D. National Center for PTSD—Matthew Friedman, M.D. VA Research—Tim Gerrity, Ph.D. Geriatric Research, Education, and Clinical Centers—Marsha Goodwin, R.N., M.A., M.S.N. Discussion
5:15–6:00	Public Comment on Purpose and Goals of a National Center(s) William Brew—Paralyzed Veterans of America Matt Puglisi—The American Legion Paul Sullivan—National Gulf War Resource Center

APPENDIX B

Public Law 105-368: The Veterans Program Enhancement Act of 1998, Sec. 103. National Center on War-Related Illnesses and Post-Deployment Health Issues

(a) Assessment. The Secretary of Veterans Affairs shall seek to enter into an agreement with the National Academy of Sciences, or another appropriate independent organization, under which such entity shall assist in developing a plan for the establishment of a national center or national centers for the study of war-related illnesses and post-deployment health issues. The purposes of such a center may include:

(1) carrying out and promoting research regarding the etiologies, diagnosis, treatment, and prevention of war-related illnesses and post-deployment health issues; and

(2) promoting the development of appropriate health policies, including monitoring, medical recordkeeping, risk communication, and use of new technologies.

(b) Recommendations and Report. With respect to such a center, an agreement under this section shall provide for the Academy (or other entity) to:

(1) make recommendations regarding: (A) design of an organizational structure or structures, operational scope, staffing and resource needs, establishment of appropriate databases, the advantages of single or multiple sites, mechanisms for implementing recommendations on policy, and relationship to academic or scientific entities; (B) the role or roles that relevant Federal departments and agencies should have in the establishment and operation of any such center or centers; and (C) such other matters as it considers appropriate; and

(2) report to the Secretary, the Secretaries of Defense and Health and Human Services, and the Committees on Veterans' Affairs of the Senate and

House of Representatives, not later than 1 year after the date of the enactment of this Act, on its recommendations.

(c) Report on Establishment of National Center. Not later than 60 days after receiving the report under subsection (b), the Secretaries specified in subsection (b)(2) shall submit to the Committees on Veterans' Affairs and Armed Services of the Senate and the Committees on Veterans' Affairs and National Security of the House of Representatives a joint report on the findings and recommendations contained in that report. Such report may set forth an operational plan for carrying out any recommendation in that report to establish a national center or centers for the study of war-related illnesses. No action to carry out such plan may be taken after the submission of such report until the end of a 90-day period following the date of the submission.