

## APPENDIX E

# Strategies to Protect the Health of Deployed U.S. Forces: Medical Surveillance, Record Keeping and Risk Reduction—Executive Summary

Nine years after Operations Desert Shield and Desert Storm (the Gulf War) ended in June 1991, uncertainty and questions remain about illnesses reported in a substantial percentage of the 697,000 service members who were deployed. Even though it was a short conflict with very few battle casualties or immediately recognized disease or non-battle injuries, the events of the Gulf War and the experiences of the ensuing years have made clear many potentially instructive aspects of the deployment and its hazards. Since the Gulf War, several other large deployments have also occurred, including deployments to Haiti and Somalia. Major deployments to Bosnia, Southwest Asia, and, most recently, Kosovo, are ongoing as this report is written. This report draws on lessons learned from some of these deployments to consider strategies to protect the health of troops in future deployments.

In the spring of 1996, Deputy Secretary of Defense John White met with leadership of the National Research Council and the Institute of Medicine to explore the prospect of an independent, proactive effort to learn from lessons of the Gulf War and to develop a strategy to better protect the health of troops in future deployments.

The study presented in this report developed from those discussions. The U.S. Department of Defense (DoD) sought an independent, external, and unbiased evaluation of its efforts regarding the protection of U.S. forces in four areas: (1) assessment of health risks during deployments in hostile environments, (2) technologies and methods for detection and tracking of exposures to a subset of harmful agents, (3) physical protection and decontamination, and (4) medical

protection, health consequences and treatment, and medical record keeping. Studies that have addressed topics 1, 2, and 3 have been carried out concurrently by the Commission on Life Sciences and the Commission on Engineering and Technical Systems of the National Research Council.

The study presented here, carried out with staff support from the Medical Follow-up Agency of the Institute of Medicine, addresses the topics of medical protection, health consequences and treatment, and medical record keeping. The study team was charged with addressing the following:

- Prevention of adverse health outcomes that could result from exposures to threats and risks including chemical warfare and biological warfare, infectious disease, psychological stress, heat and cold injuries, unintentional injuries;
    - Requirements for compliance with active duty retention standards;
    - Predeployment screening, physical evaluation, and risk education for troops and medical personnel;
      - Vaccines and other prophylactic agents;
      - Improvements in risk communication with military personnel in order to minimize stress casualties among exposed or potentially exposed personnel;
      - Improvements in the reintegration of all troops to the home environment;
      - Treatment of the health consequences of prevention failures, including battle injuries, disease and non-battle injury (DNBI), acute management, and long-term follow-up;
        - Surveillance for short- and long-term outcomes, to include adverse reproductive outcomes; and
        - Improvement in keeping medical records, perhaps using entirely new technology, in documenting exposures, treatment, tracking of individuals through the medical evacuation system, and health/administrative outcomes.
- (Statement of Task, Appendix B)

Within the breadth of this charge, the study team chose to emphasize areas in which greatest needs were evident from the lessons learned from the Gulf War and other recent deployments and to treat other areas (those areas where the study team believed that it had little to offer the military) less thoroughly. Since an important motivating force for the study was the health and reproductive concerns of veterans after the Gulf War, the study team chose to focus on the major challenges for prevention and data needs indicated by the health problems widely reported by deployed forces after the Gulf War and the efforts to better understand them.

What were the lessons of the Gulf War? Briefly, one of the lessons was that even in the absence of widespread acute casualties from battle, war takes its toll on human health and well-being long after the shooting or bombing stops. Although military preventive medicine programs have developed reasonably effective countermeasures against many of the discrete disease and non-battle in-

jury hazards of deployment, they have not yet systematically addressed the medically unexplained symptoms seen not only after the Gulf War but also after major wars dating back at least to the Civil War. The health problems reported by veterans after the Gulf War also brought out two other major and interrelated needs for improvements in preventive care for deployed forces. One is for a health surveillance system with documentation so that health events in the field are noted and responded to. Closely allied is the need for an automated medical record that can provide information about a service member's health events over his or her service career and into civilian life after military service. These three topics of medically unexplained symptoms, medical surveillance, and medical record keeping form the critical areas of emphasis of the report.

Although the study team considered the service member's life cycle of recruitment, predeployment, deployment, and postdeployment to include separation from the service, the postdeployment period appeared to be a time when, in particular, additional effort could be crucial in attending to the health of the deployed forces. The report discusses needs and opportunities for improved surveillance, special focused health care, and assistance with reintegration into the home environment during this time.

Two other major issues emerged as the study group went about its work. One serious challenge to the protection of deployed U.S. forces is that of providing the National Guard and Reserve components with the preparation and health surveillance afforded the active-duty component. The reserves play an increasingly important role in military deployments. Yet, their lack of access to the military health care system while they are inactive places serious limitations on the routine health care that they receive and the ability to monitor their health status over both the short and long term after a deployment. This problem for the reserves highlights a challenge for many active-duty service members after they separate from military service. To the extent that they receive their health care in the civilian sector and not through the U.S. Department of Veterans Affairs (VA), the capture of any data on their health care is problematic, as is the concept of a true lifetime medical record as promised by President Clinton in 1997 (White House, 1997).

A second issue that the study team came to recognize as a serious concern was that although there have been encouraging changes in DoD policy with new emphasis on what is termed Force Health Protection, these changes have not yet been reflected in the structural and cultural changes that will be needed within the services and DoD so that they may carry out the laudable new policies. Effective application of an improved health surveillance system and an integrated computer-based patient record will require concerted leadership and coordination to prevent the inexorable tendency toward "stovepiping"—that is, the development or continuation of an array of independent task- or service-specific systems that cannot meet the current needs for information exchange and follow-up.

High-level leadership and coordination are also needed to effect changes in the way in which medically unexplained symptoms are addressed in military populations. Although the problem is not unique to the military, it is regularly seen in populations who have participated in major deployments and will likely be observed after future deployments. Efforts to intervene to try to prevent or ameliorate medically unexplained symptoms are needed, as are careful evaluations of these efforts and a related research program.

Need for additional high-level leadership and coordination for military public health and preventive medicine run counter to current momentum within DoD. The medical structure of DoD is focused on the delivery of health care and the operation of the Tri-Care program (the military health maintenance organization). The costs of the health care delivery system are enormous, and management of the health care delivery system has come to dominate the DoD's medical leadership. High-quality health care is crucial to recruitment and retention of good service members, but in the current environment, the practice of military preventive medicine and military medicine appears to compete very poorly for personnel, funding, and leadership resources.

Nevertheless, DoD has made considerable efforts in several areas relevant to this study since the Gulf War. An important step occurred in November 1998, when the National Science and Technology Council (NSTC) released a plan in response to a Presidential Review Directive (National Science and Technology Council, 1998). Developed by an interagency task force with representatives from DoD, VA, and the U.S. Department of Health and Human Services (DHHS), the plan is entitled, *A National Obligation: Planning for Health Preparedness for and Readjustment of the Military, Veterans, and Their Families after Future Deployments*. The plan describes many laudable goals related to health during deployments, record keeping, research, and health risk communication that the government should implement to better safeguard military forces. Taking those efforts into account, with this report the study team proposes additional and complementary strategies to more effectively address medically unexplained symptoms, medical surveillance, and medical record keeping for future deployments, as well as other aspects of prevention such as risk communication and reintegration. The report emphasizes the need to extend medical surveillance and record keeping and other protections to the reserve components.

## MEDICALLY UNEXPLAINED SYMPTOMS

*Medically unexplained symptoms* is the term used in this report to refer to symptoms that are not clinically explained by a medical etiology and that lead to use of the health care system. They are increasingly recognized as prevalent and persistent problems among civilian populations, in which they are associated with high levels of subjective distress and functional impairment with extensive

use of health care services (Hyams, 1998; Engel and Katon, 1999). In military populations, similar medically unexplained symptom-based conditions have been observed after military conflicts dating back to the Civil War (Hyams et al., 1996) and are anticipated after future deployments (Presidential Advisory Committee on Gulf War Veterans' Illnesses, 1996b).

Clinicians and other persons working in medical surveillance must recognize that medically unexplained symptoms are just that; namely, there are no current explanations for them. Therefore, communicating the limits of modern medicine coupled with a compassionate approach to patients with medically unexplained symptoms is essential to the management of such patients. Until clear etiological factors are identified, the health care professional relies upon a body of knowledge about the management of these symptoms that has proven to be effective in many cases. Although a program of primary prevention is not feasible given the current state of knowledge, enough is known to recommend the implementation of a secondary prevention strategy. Good clinical evidence indicates that medically unexplained symptoms are much harder to treat and ameliorate once they have become chronic. It is thus important to identify the patient with medically unexplained symptoms early, when there may be a greater opportunity to restore the patient to his or her previous level of function. Providers with the clinical skills needed for medical management of these patients can then work with them toward a mutually agreed upon set of therapeutic goals that include striving to cope with residual symptoms and rehabilitation in the absence of a definitive diagnosis.

### **Recommendations<sup>1</sup>**

**The study team recommends that the U.S. Department of Defense develop an improved strategy to address medically unexplained symptoms, involving education, detection, evaluation, mitigation, and research. (Recommendation 6-9.<sup>2</sup>)**

- **Undertake a program of continuing education for military primary care providers to improve their clinical ability to diagnose, treat, and communicate with patients with medically unexplained symptoms. Incorporate the topic into the curricula of military graduate medical education programs such as the Uniformed Services University of the Health Sciences and the service schools for medical personnel. To the extent possible, make information about medically unexplained symptoms available and accessible to**

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<sup>1</sup>Because of the large number of recommendations in this report, a subset are presented in this Executive Summary.

<sup>2</sup>Recommendation 6-9 is Recommendation 9 in Chapter 6.

service members and to civilian health care providers for members of the reserves.

- Carry out a pilot program to identify service members in the early stages of development of medically unexplained symptoms through the use of routinely administered self-report questionnaires (examples are noted in Chapter 6) and through informed primary care providers.

- Evaluate the efficacy of the pilot secondary prevention and treatment program, including the ability of screening questionnaires to detect early stages of medically unexplained symptoms.

- Treat medically unexplained symptoms in the primary care setting whenever possible, with referral to more intensive programs as necessary.

- Carry out a research program with prospective studies to assess the role of predisposing, precipitating, and perpetuating factors in medically unexplained symptoms. As feasible, involve academic health centers in the research efforts.

## MEDICAL SURVEILLANCE

The military has launched many medical or health surveillance initiatives in the last several years in response to the problems highlighted by the Gulf War illnesses. Pre- and postdeployment questionnaires and blood draws, periodic health assessments, baseline health surveys for recruits, and improved systems for the tracking of inpatient and ambulatory care visits during deployments have all been planned or implemented to various degrees.

The multiplicity of medical surveillance-related tools that have developed reflects a genuine effort on the part of DoD and the individual services to better track and document the health of deployed forces. However, with no central authority for military public health, the tools lack coordination as part of an overall plan for achieving public health goals.

### Recommendation

**Clarify leadership authority and accountability for coordination of preventive medicine and environmental and health surveillance across the U.S. Department of Defense and the individual services.**

(Recommendation 4-16.)

Part of the work of such a body would be to coordinate and potentially consolidate the surveillance tools referred to above, such as the Recruit Assessment Program to gather baseline data from incoming recruits, the Health Evaluation and Assessment Review (HEAR) and other sources of pre- and postdeployment

self-reported health status data, surveillance systems for use during deployments, exposure assessment and environmental surveillance measures, and laboratory-based surveillance. Since these tools and systems were developed independently, they do not necessarily work toward shared purposes. The study team makes the following recommendations in considering these surveillance tools as part of an armamentarium of surveillance means.

### **Recommendations** (additional recommendations are in Chapter 4)

- **The Recruit Assessment Program should be implemented to collect baseline health data from all recruits (active-duty, National Guard, and Reserve), and should be periodically reassessed and revised in light of its goals. Its data should be used prospectively to test hypotheses about predisposing factors for the development of disease, injury, and medically unexplained symptoms.** (Recommendation 4-1.)
- **Annually administer an improved Health Evaluation and Assessment Review (HEAR) to reserve as well as to active-duty personnel to obtain baseline health information. Refine the Health Evaluation and Assessment Review by drawing on additional survey instrument and subject matter expertise.** (See full Recommendations 4-2a and 4-2b.)
- **Reinforce the laboratory capability for public health surveillance within the military. Mandate central reporting of laboratory findings of reportable conditions.** Continue to provide increased resources to overseas laboratories for surveillance in regions of military interest. (See full Recommendation 4-6.)
- **Discontinue pre- and postdeployment health (versus readiness) questionnaires unless they are warranted for military reasons other than gathering baseline and postdeployment health status information.** (See full Recommendation 4-7.)
- **As quickly as possible, implement a deployment disease and non-battle injury surveillance system that is integrated with the patient care information system and that automatically reports information to a central medical command.** Continue efforts to capture data at the individual level as well as at aggregate levels during deployments. (See full Recommendation 4-8.)
- **Integrate the efforts of environmental surveillance, preventive medicine, clinical, and information technology personnel to ensure the inclusion of medically relevant environmental and other exposures in the individual medical record.** (Recommendation 4-9.)

Given the experiences after the Vietnam and Gulf wars, the postdeployment period is crucial for carrying out medical surveillance and providing appropriate care for returning service members. The Veterans Benefits Improvement Act of 1998 (P.L. 105-368) provides that service members will be eligible for medical care for a period of 2 years after their return from service in a theater of combat operations during a period of war or hostilities. The provision of this care without the need for establishing service-connection provides a valuable opportunity to ascertain the health needs of this population, including those related to medically unexplained symptoms. Rather than naming a special deployment-specific registry, veterans should be able to receive care as needed from the designated sources. It will be important to determine who uses this care and how well data surrounding this care can be captured from DoD and VA providers and their contractors. To gather postdeployment health status information from a more representative sample of veterans after deployments, a self-report survey could be used.

### Recommendations

Carry out studies to evaluate the data captured from the 2 years of care provided after a deployment. Try to determine the extent to which the data are representative of the population of service members who deployed and whether they could be used to indicate the health of service members after a deployment. (Recommendation 4-10.)

- **Annually administer Health Evaluation and Assessment Review (HEAR) to a representative sample of service members who have been separated from the service for 2 to 5 years after a major deployment to track health status and identify health concerns including medically unexplained symptoms.** Also administer the HEAR to those separated service members who seek health care during the 2 years after a deployment. Evaluate the validity and usefulness of the information collected. (Recommendation 4-11.)
- **Avoid whenever possible the creation of deployment-specific registries. Depend, instead, on the data provided by routine medical care under the Veterans Benefits Improvement Act of 1998 (P.L. 105-368) and the annual Health Evaluation and Assessment Review.** (Recommendation 4-12.)

### POSTDEPLOYMENT REINTEGRATION

The changing demographics of deployed forces, increased operational tempo, and increased reliance on the reserve component bring heightened needs for support services for service members and their families both during and after

deployments. It is crucial that service members returning from deployments have seamless access to health care and support services and be made aware of the resources available to them. Since the Gulf War, the service components have made progress in providing support services to service members and families during reintegration, but the programs have not been adequately evaluated.

### Recommendations

- **Planning and operational documents for military deployments should be required to include plans for supporting the return and reintegration of active-duty and reserve service members involved in the deployment and should specify the strategies that should be used to address anticipated problems, the resources needed to carry them out, and proposals for how the resources will be made available.** (See full Recommendation 7-1.)
- **Carry out research into the needs of service members and their families during deployments and upon reintegration into the home environment. Use the findings to reevaluate programs and policies.** (See full Recommendation 7-3.)

### MEDICAL RECORD KEEPING

Previous studies have cited deficiencies in medical record keeping as a major impediment to understanding and treating the health effects associated with deployment to the Gulf War (Institute of Medicine, 1996a; Presidential Advisory Committee on Gulf War Veterans' Illnesses, 1996b). The study team and other health information experts consider the computer-based patient record essential for DoD to meet the health care needs of service members before, during, and after deployments. In 1996, the Presidential Advisory Committee on Gulf War Veterans' Illnesses directed the NSTC to develop an interagency plan to address health preparedness for and readjustment of veterans and families after future conflicts and peacekeeping missions (Presidential Advisory Committee on Gulf War Veterans' Illnesses, 1996b). NSTC subsequently recommended that DoD "implement a fully integrated computer-based patient record available across the entire spectrum of health care delivery over the lifetime of the patient" (National Science and Technology Council, 1998, p. 23). To serve the military health system needs, the computer-based patient record (CPR) system must meet several needs simultaneously:

1. provide access to an individual's health data anytime and anywhere that care is required,
2. support record keeping for the administration of preventive health services,

3. facilitate real-time medical surveillance of deployed forces and timely medical surveillance of the total force,
4. provide comprehensive databases that support outcomes studies and epidemiological studies, and
5. maintain longitudinal health records of service members beginning with recruitment and extending past the time of discharge from the military.

During the course of the study, the team heard briefings on several military health information system projects. In general, each need for health data has been addressed by a separate data-gathering activity at the individual service level. No central oversight authority common to all three services was apparent to ensure that independent efforts are coordinated or, better yet, consolidated into a single activity that serves the needs of all three services. The military health system has adopted a “best of breed” approach, in which task-specific software applications are interfaced together. This strategy takes advantage of multiple niche products, but it presents a significant challenge to the integration of data because of the lack of a common data model or a common database. To the extent possible, the needs of all three services should be considered concurrently to maximize the reuse of data and software programs.

In addition to the development of technical plans for data integration, organizational plans need to be developed to standardize policies and practices related to medical record keeping. Currently, guidelines for medical record documentation vary on the basis of the type of data involved (e.g., outpatient, inpatient, and immunization information), the location of the service member (e.g., garrison, deployed, and location of deployment), and the branch of service. Policies, procedures, and practices should be standardized to store consistent and comprehensive data in the computer-based patient record (CPR) throughout the military.

### **Recommendations**

**(additional recommendations are in Chapter 5)**

- **Clarify leadership authority and accountability for establishment of an integrated approach to the development, implementation, and evaluation of information system applications across the military services. Establish a top-level technical oversight committee responsible for approving all architectural decisions and ensuring that all application component selections meet architecture and data standards requirements.** (Recommendation 5-1.)
- **Coordinate the evaluation of information needs for maximum reuse of data elements, data-gathering instruments (e.g., surveys), and software systems across the military health system.** (See full Recommendation 5-2.)

- **Develop standard enterprisewide policies and procedures for comprehensive medical record keeping that support the information needs of those involved with individual care, medical surveillance, and epidemiologic studies.** (Recommendation 5-3.)
- **Develop methods to gather and analyze retrievable, electronically stored health data on reservists.** (See full Recommendation 5-6.)

There are many challenges to the development, implementation, and maintenance of a health information system to serve the diverse needs of the military. It is not surprising that there are separate activities in each of the services. In some cases these separate activities are driven by immediate needs, and in other cases they arise out of a lack of awareness of existing solutions or projects under way elsewhere. To meet the needs of U.S. forces deployed abroad, however, a unified CPR system is essential. The study team recommends that a comprehensive review of the military health information systems strategy be undertaken to enumerate the information needs; define an expedient process for development of an enterprisewide technical architecture, common data model, and data standards; identify critical dependencies; establish realistic time lines; assess the adequacy of resources; and perform a realistic risk assessment with contingency plans.

The process of developing an integrated CPR for the military health care system is complex yet essential to ensuring military readiness and a healthy force. It involves a tremendous expenditure of money and resources and requires extensive expertise. With so much at stake, the study team recommends that an external advisory board participate in the effort by providing ongoing review and advice regarding the military health information systems strategy. Composed of members of academia and industry, this group would provide synergy and potential leverage between the military and civilian sectors in information systems. The study team believes that this partnership will increase the likelihood of success of the overall endeavor.

### **Recommendations**

**Conduct an independent risk assessment of the military health information systems strategy and implementation plan. Establish an external advisory board that reports to the Secretary of Defense and that is composed of members of academia, industry, and government organizations other than the Department of Defense and the Department of Veterans Affairs to provide ongoing review and advice regarding the military health information system's strategy and implementation.** (Recommendation 5-4.)

Given the mandatory nature of medical data collection in the military, including sensitive information (e.g., human immunodeficiency virus infection status and mental health status), stringent regulations, policies, and procedures are necessary to maintain system security and protect the confidential medical information of all service members and their dependents.

### **Recommendation**

**Make available to service members the regulations, policies, and procedures regarding system security and protection of individually identifiable health information for each service member.** (See full Recommendation 5-7.)

## **RISK COMMUNICATION**

Risk communication has come to describe a process of concerted information and opinion exchange among individuals, groups, and institutions (National Research Council, 1989). The study team believes that a clear commitment to improvements in risk communication is needed from DoD. Responsibility should be designated to attempt a change in the culture within DoD and the military services so that dialogue and exchange about risks are facilitated at all levels. Aspects of risk communication need to be incorporated into the training programs for line commanders and health care providers. Furthermore, discussion is needed within DoD and the services about what problems the tool of risk communication may be used to try to solve. Such a discussion can lead to goals for reducing those problems and means of evaluation and improvement.

The risk communication efforts associated with the vaccination against anthrax, the risk communication goal articulated in Presidential Review Directive 5, the guide developed in response to recommendations from earlier independent advisory bodies, and the *Comprehensive Risk Communication Plan for Gulf War Veterans* (Persian Gulf Veterans Coordinating Board, 1999) are encouraging signs that the importance of risk communication has been acknowledged within some quarters at DoD. An additional indication of commitment to a cultural change throughout the entire system is needed from the top.

### **Recommendation**

**Although responsibility for risk communication must permeate all levels of command, the U.S. Department of Defense (DoD) should designate and provide resources to a group within DoD that is given primary responsibility for developing and implementing a plan to achieve the risk communication goal articulated in the Na-**

**tional Science and Technology Council's Presidential Review Directive 5. (Recommendation 6-1.) Such a plan should**

- **Involve service members, their families, and outside experts in developing an explicit set of risk communication topics and goals. In other words, decide what information people need to know and when they need to know it.**
- **Consider how to deliver the information, including the intensity of communication needed for different types of risks. Some topics will necessitate full, ongoing dialogue between the involved parties, whereas others will require less extensive efforts. Incorporate procedures to evaluate the success of risk communication efforts and use these evaluations to revise the communication plan as needed.**
- **Include a response plan to anticipate the inevitable appearance of new risks or health concerns among deployed forces. The plan should include a process for gathering and disseminating information (both about the risks themselves and about the concerns of the troops) and for evaluating how communications about these issues are received and understood by service members and their families.**
- **Educate communicators, including line officers and physicians, in relevant aspects of risk communication.**
- **Carry out the interagency applied research program described in Presidential Review Directive 5, Strategy 5.1.2.**

## **RESERVES**

Several of the most important components of a strategy to protect the health of deployed forces (improved medical surveillance and care that is responsive to medically unexplained symptoms, record keeping, risk communication, the use of preventive measures, and reintegration into the home environment) pose particular challenges for the reserve component because of their quasicivilian status and geographically dispersed situation. Since the Ready Reserve now constitutes almost half of the total force and is a significant component of deployed forces, the needs of the reserves cannot be ignored or postponed. Although their special circumstances make it impossible to mandate a health protection strategy identical to that for the active-duty forces, a coherent strategy should be developed to provide similar programs working toward the same ends that are provided with adequate resources.

### Recommendation

**Include the reserves in the planning, coordination, and implementation of improved health surveillance, record keeping, and risk communication. Develop a strategy for the reserve forces that takes into consideration their limited access to the military health care system before and after deployments but that recognizes their particular needs for health protection and that provides adequate resources to meet those needs.** (See full Recommendation 8-1.)

### CONCLUSIONS

Since the Gulf War, DoD has demonstrated much greater awareness of the importance of medical surveillance and record keeping in protecting the health of its deployed forces. It has launched or planned a variety of initiatives to address acknowledged shortcomings in these areas. These efforts suffer from a lack of the concerted planning required for efficient use of systems and resources. For medical surveillance this might be addressed with leadership and coordination in the area of military public health. With medical record keeping, outside expert review is needed to provide ongoing input into the challenging effort of implementing a successful CPR for the military.

The medically unexplained symptoms reported by veterans after the Gulf War have motivated many of DoD's constructive changes in medical surveillance and medical record keeping, but these initiatives cannot be anticipated to prevent them after future deployments. Indeed, it is not yet known how medically unexplained symptoms can be prevented. Better medical surveillance and record keeping can lay the foundation so that similar questions can be more readily answered in the future, however, and permit better insights into questions of etiology. The study team urges a research effort to obtain a better understanding of predisposing, precipitating, and perpetuating factors for these conditions. In the meantime, steps should be taken to identify those suffering from medically unexplained symptoms and intervene with management and treatment of symptoms to mitigate them and prevent chronicity. The efficacies of these steps should be evaluated.