

Recommendations of the Research Advisory Committee on Gulf War Veterans' Illnesses Regarding the Planned "Follow-Up Study of a National Cohort of Gulf War and Gulf War Era Veterans," adopted Nov. 2, 2010.

The Committee recommends that VA suspend current plans to field the "Follow-Up Study of a National Cohort of Gulf War and Gulf War Era Veterans," the large longitudinal survey under development by VA's Office of Public Health and Environmental Hazards, pending extensive revisions of the survey instrument.

The Committee continues to consider longitudinal assessment of the health of Gulf War veterans to be an essential element of the federal Gulf War research effort. Unfortunately, as currently designed, the proposed survey fails to collect data on the most pressing health issues related to Gulf War service, while collecting excessive information on more peripheral concerns.

Major examples include:

- No follow-up on essential elements of VA's initial survey of Gulf War veterans
- Lack of systematic, comprehensive data on symptoms associated with Gulf War service
- Lack of systematic, comprehensive data on diagnosed medical conditions
- Lack of information on the health of veterans' family members
- Lack of information on veterans' use of health care services and treatments

The Gulf War longitudinal study represents a major commitment of time and funding. It should be designed as an integral part of VA's new Gulf War research program, and support the objectives of the program. Extensive revisions should be undertaken in conjunction with researchers outside VA who have specific expertise in assessing the health problems of Gulf War veterans, and should be reviewed and approved by the Gulf War Research Steering Committee.

The Committee became aware of the pending survey only through the chance observation by a veteran who noticed a Federal Register posting required by the Paperwork Reduction Act disclosing the existence of the survey. The posting did not include the survey itself. Committee staff then requested and were given a copy of the survey. The Research Advisory Committee and the Gulf War Research Steering Committee should each have been provided the opportunity to review the survey prior to posting. Without having had the opportunity to undertake an exhaustive review, the Committee notes the following examples of deficiencies to be addressed:

The survey fails to collect the most important types of data required to assess priority health issues specific to Gulf War service, while collecting detailed information in areas that are less pressing. This is reflected, overall, by the relatively few questions that provide data on undiagnosed symptomatic illness and diagnosed medical conditions, compared to the many pages of questions devoted to psychological problems and digestive issues.

Undiagnosed symptoms and symptom complexes are the most prevalent health concern resulting from Gulf War service. The proposed survey collects only limited data on symptoms of selected types. Further, symptoms in different areas are not queried in a consistent way, and are not consistent with symptom data collected in VA's initial Gulf War survey. As a result, survey data will not provide clear, systematic information either on veterans' current symptoms or changes in their symptoms over time, and cannot be used to construct a representative case definition for Gulf War illness.

Federal advisory panels and Congressional committees have called on VA to determine if Gulf

War veterans have excess rates of neurological diseases such as multiple sclerosis and Parkinson's disease, or increased rates of cancers and other diagnosed medical conditions. But 20 years after the Gulf War, we still know very little about the prevalence of diagnosed medical conditions in Gulf War veterans. It is extremely important that this survey obtain systematic data on physician-diagnosed medical conditions, as well as information on hospitalizations and surgeries since the Gulf War. Examples of the types of data required include information on specific neurological diagnoses and difficult-to-diagnose neurological conditions, data on specific cancer types and noncancerous tumors, migraines, autoimmune conditions, chronic infectious diseases, respiratory conditions, dermatological conditions, gastrointestinal conditions, and cardiovascular conditions.

The survey currently includes an extensive number of questions related to psychological problems (e.g., depression, anxiety, PTSD, substance abuse). While problems of this nature are found in Gulf War veterans, they are less common than in other war veterans, and there is no reason they should constitute such a large proportion of the Gulf War survey instrument. Similarly, the current survey devotes nearly four pages to detailed questions on gastrointestinal function and symptoms, giving them much more emphasis than other problems of importance.

The survey does not include questions related to the health of veterans' family members, although this remains a concern for Gulf War veterans. Important areas for which systematic data are needed include information on children's health—both congenital abnormalities and problems that develop later in life (e.g. childhood cancers, developmental disorders of learning and attention), and information on birth outcomes and fertility.

Although the last section of the survey includes questions on veterans' use of several complementary and alternative medical (CAM) therapies, there is no systematic information collected on veterans' use of healthcare services at VA and elsewhere, or their use of more conventional treatments at VA and elsewhere. There have been some indicators that most veterans with Gulf War illness do not use VA healthcare services, but that some may use services more intensively than veterans of other eras. It is not known if veterans with Gulf War illness have benefited from care provided by VA and outside sources, or from any specific treatments. It is also not known what proportion of veterans with Gulf War illness and other medical conditions have applied for and received disability benefits. Current data in these areas would be extremely useful.

Several sections of the survey should include an "other" category to allow veterans to provide information that would otherwise be lost when the respondent is limited by choices provided in the questionnaire.

With the planned expansion of the Gulf War brain bank/tissue repository, the survey presents an opportunity to provide information on tissue and organ donation to the large group of Gulf War-era veteran survey participants. A brief introduction to the program could be provided, along with contact information for those interested in learning more.