

Committee Discussion

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Research Advisory Committee on Gulf War Veterans Illnesses
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National Survey Response Discussion

- The Federal Register posting dated September 7, 2010 addressed the proposed "Follow-up Study of a National Cohort of Gulf War and Gulf Era Veterans," reference OMB Control N. 2900-New (VA Form 10-0488).
- The justification letter sent with the proposed questionnaire states: "This research, which will occur in conjunction with the 20th anniversary of the first Gulf War, is essential for the VA to plan and provide better health care for these Veterans and develop an improved understanding of the natural history of chronic conditions such as CFS and unexplained multisymptom illnesses."
- A survey instrument on a large existing longitudinal cohort can provide the best opportunity to gather important data regarding symptoms, assigned diagnoses, and illness trajectories. This survey should thus form an important part of the foundation for a comprehensive research plan. However, the current survey fails to accomplish this goal.

National Survey Response Discussion

- This survey questionnaire should have been submitted to the newly formed Steering Committee on Gulf War Veterans Research for their input and for coordination with the rest of the planned new large VA research efforts on GW illness.
- The current survey questionnaire appears top-heavy with regard to psychological and substance abuse questions as well as very detailed questions regarding gastrointestinal complaints while it accomplishes very little with regard to a systematic evaluation of health symptoms. Simply asking veterans whether they believe they have an unexplained multisymptom illness is not as adequate as obtaining data on specific health symptoms.
- There is no systematic collection of data on physician-diagnosed diseases (neurological conditions, cancer types, autoimmune disorders, etc.).

Recommendations

- A. Prior to finalization, the survey should be reviewed and revised in detail by the VA Gulf War Research Steering Committee.
- B. The following aspects of the survey should particularly be addressed:
 1. Questions should be added regarding the full range of specific symptoms that may be experienced by Gulf War veterans, which could lead to a better case definition of, or diagnostic criteria for, Gulf War illness. The Health Symptom Checklist or other relevant symptom questionnaires might be used.

Recommendations

- 2.** The survey should query specific neurological and autoimmune diseases for which current rates of diagnosis are unknown in Gulf War veterans. These should include multiple sclerosis, Parkinson's disease, dementia, lupus, and non-cancerous tumors (with particular emphasis on brain tumors). In addition, queries regarding cancer diagnosis should specifically ask what type of cancer was diagnosed.

Rates of ALS and motor neuron disease are also important, although very few respondents will report this diagnosis. Brain cancer rates are extremely important to further quantify in GW veterans and should be queried; questions could include when diagnosis was made and what type of brain tumor was present. Non-cancerous brain tumors should also be queried.

There should be a question regarding diagnosis of peripheral neuropathy and possibly a question about symptoms of peripheral neuropathy. Questions regarding cirrhosis should be followed by asking if the diagnosis was alcohol-related or not.

Recommendations

- 3.** There are no questions regarding GW veteran children's health or miscarriages in female veterans. These questions are important because many GW veterans are concerned about their children's health and about fertility. Questions regarding children's health should ask about congenital abnormalities (Goldenhar syndrome, Down syndrome etc.), diagnosis of developmental disorders of learning and attention, and diagnosis of uncommon childhood illnesses (cancers, tumors etc.).
- 4.** Most sections of the survey instrument regarding diagnoses and treatments should also include an "other" category in which the participant can report other pertinent diagnoses or treatments. This strategy is often a very useful way to obtain information that would otherwise be lost if the respondent is limited by the choices given only in the questionnaire. This is particularly salient for the web-based survey, on which respondents are not able to write in additional information on the survey form itself.

Recommendations

5. In the last section of the survey, in which complementary and alternative (CAM) treatments are queried, there is no question regarding whether the respondent uses VA healthcare services for traditional treatments. This question should be added in addition to asking why health care is not utilized at the VA if it is not being used. This will allow VA to understand why some veterans do not use VA health care services. It may also be useful to add a section here asking if the participant has applied for disability through the VA and if he/she is service connected or not.
6. With the planned expansion of the Gulf War Brain Bank, the survey presents a good opportunity to provide a brief introduction to the idea of organ donation in this large group of nearly 10,000 anticipated GW veteran respondents. Introduction to the GW brain donation program might be accomplished by a brief introduction letter as a separate attachment in the survey mailer that would include website and contact telephone numbers for GW Brain Bank staff who can answer questions for those wishing to learn more about VA's organ donation program.

Final GW Task Force Report Discussion

Suggested edits from a subgroup of RAC Committee:

- Many suggested edits were addressed that were not related to research topics.
- For example, on the clinical education/training section (Perception 3A, p. 12) included the phrase, "VA health care providers are not fully educated on managing the Gulf War Veterans health-related needs or their concerns regarding potential hazardous exposure."

It was felt that this statement focused training needs on the veterans "concerns" regarding exposures (i.e. psychological effect), rather than on the exposures themselves. The suggestion was to change the sentence to read, "....health-related needs or their potential hazardous exposures."

This edit was made in the Final Task Force Report as were other similarly suggested edits.

Final Gulf War Task Force Report Discussion

- However, most suggested edits related to research topics, were not changed or edited in the final report.
- For example, it was suggested that DU exposures from armored divisions with tank exposures and during the Camp Doha fire should be studied to assess the potential long-term health effects of inhaled and ingested DU and not just from embedded DU fragments. This suggestion was not addressed or incorporated in the report.
- Also, it was suggested that most of the appendixes be removed because they were outdated and reflected the old culture that the task force report sought to replace. Although a few appendixes had minor modifications made to them, they were not removed or adequately changed to address the concerns that were raised.
- VA has suggested that this will be the first GW Task force report and not the last. It is hoped that future editions will also seek input from relevant stakeholders and that suggested edits will seriously be taken into consideration for all parts of the report.

Director of Deployment Health Research

- New Position being created by VA
- Deadline for applications - November 17th
- Need for clarification regarding scope of responsibilities of this position

ANNUAL OPERATIONS PLAN DISCUSSION

2011 Annual Operations plan Discussion

Charter and Statutory Mission:

1. Review research findings and research plans regarding health consequences of GW service.
2. Evaluate research against the standard of whether it makes a difference to the health of GW veterans.

2011 Objectives

1. Advise re: establishment of effective new VA GWI research program, providing timely recommendations throughout year in light of past experience and review of proposed plans and RFA's.
2. Review and disseminate relevant new research literature.
3. Identify promising novel treatments, diagnostic markers, and promising mechanisms underlying GWI that constitute potential targets for treatment.
4. Provide a short scientific report to Secretary summarizing major new literature findings and new research opportunities identified in 2009-2010.

Meeting Speaker Themes

- Themes will include crosstalk pathways between innate immunity and the central nervous system in autoimmune diseases as well as toxicogenomics and development of chronic disease states.
 - For example, presentations regarding MS and Lupus mechanisms as examples of complex autoimmune states. Also, presentations regarding gene-environment interactions and chronic health effects and whether particular genetic polymorphisms result in greater susceptibility of chronic illness.
- Presentations regarding recently completed treatment trials for GWI and potential new treatment trial avenues that could be employed in GWI research.
 - For example, whether anti-inflammatory minocycline appears effective in animal models of GWI? Also, whether antioxidants including Co-Q10 appear effective or others should be tried that have been shown to reduce neuroinflammation and improve mitochondrial function (quercetin, luteolin) and whether mifepristone is effective in resetting the HPA axis.
- Other Suggestions?

Government Speaker Topics

- VA briefing on the status of the planned National Survey of Gulf War veterans.
- VA briefing on Committee recommendation to update and improve information on GWI research provided to VA clinicians, including the Veterans' Health Initiative (VHI) continuing education program and the VA/DOD Clinical Practice Guidelines for Unexplained Symptoms.
- VA briefing on the environmental exposure training sessions held during the summer of 2010 through the War-related Illness and Injury Centers (WRIISC) and plans for any new research programs related to these Centers.
- A presentation by the NIH Undiagnosed Disease Program regarding its success in diagnosing and treating previously undiagnosed multisymptom illnesses.

Government Speaker Topics

- Recognize the 20th Anniversary of the Gulf War by holding the first RAC meeting of the year on the anniversary of the cease-fire ending the ground war, February 28. Invite Secretary Shinseki to address the Committee and veterans in attendance on this occasion.
- Other Suggestions?

Committee Meeting Dates

Preliminary meeting dates include:

- February 28- March 1 in Washington
- June 27-28th in Boston
- November 7-8th in Washington

Literature Review

- Begin Committee discussion of relevant new literature in a round table format with Committee members taking turns presenting papers for discussion to take advantage of the diverse scientific strengths of the Committee.

Advance Literature Review

- Zotero group for literature and meeting material reviews.
- Make sure signed up for Zotero group.
- Short tutorial.
- Call RAC office with questions or problems.

Annual Report Discussion

- Short scientific report summarizing 2009-2010 meeting insights and relevant new literature.
- Will serve as an update to the 2008 Scientific Report.
- Will have updated draft for next meeting.