Committee Discussion

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Research Advisory Committee on Gulf War Veterans Illnesses
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Gulf War Pre911 Report Recommendations

- The RAC requested and was given a briefing for the newly revised report regarding Gulf War veterans health care utilization and benefits called the Gulf War-Era Pre911 report on June 27, 2011.
- This report replaced the previous Gulf War Veterans Information System (GWVIS) reports.
- The VA's newly revised Gulf War era report provides a substantial advance in publicly available VA data and builds upon the former GWVIS reports.
- The data from this report could be very useful for monitoring the health of GW veterans over time and for flagging issues of possible concern.

Gulf War Pre911 Report Recommendations

Overall recommendations to enhance future editions of this important report include:

- A). Improve how GW 'subgroups' are defined.
- B). Establish an informative "not deployed" comparison group for the "Gulf War" subgroup to allow tracking of whether diagnoses, benefits, and deaths for the 1991 GW veterans are excessive in any categories.
- C). To improve benefits reporting, it would be helpful to include data on the number of claims filed and the number of service connected, for diagnosed medical conditions. If there were too many diagnoses to practically report, then providing general categories and special categories of interest for GW veterans (i.e. ALS, MS, PD, cancers) would be helpful.

Gulf War Pre911 Report Recommendations

D. Reporting overall totals for all tables would clarify what the data is meant to convey. Also, reporting data in tables by both the number of veterans and the percent of veterans in each category would also help clarify what the data is meant to convey and help to logical impossibilities (i.e. reporting the number of GW veterans diagnosed with endocrine disorders and the percent within each category).

Also by including stakeholders familiar with this cohort in draft versions of the report, it can be making sure that all data reported are correct, and accurately described. This would include the adoption of logic checks for data consistency in all presented data (for example, to identify and correct logical impossibilities such as data showing Gulf War veterans who, based on currently reported age (20s or early 30s), would have been far too young to have served in the 1991 Gulf War).

- Data Subgroups. Recommend that in addition to the Gulf War "Desert Storm" subgroup for which data are currently provided, the report also provide data for the following Gulf War subgroups:
 - a. Desert Shield only entered theatre after 8/06/90, departed prior to 1/16/91.
 - b. Post Desert Shield only entered theatre between 2/28/91 7/31/91, regardless of departure date.
 - c. Add suitable "Gulf War era, non-deployed" comparison group (veterans who were in the military between Aug. 2, 1990 and July 31, 1991, but did not deploy to Persian Gulf region), for data reported in all tables.

Recommendations

D. Recommend the continuation of providing special focus data for the Khamisiyah and al-Jubayl cohorts.

However, the Khamisiyah group should be further and consistently explained in the text and tables.

For example, the text indicates that they are individuals identified by DOD as being potentially exposed during service at "Khamisiyah, Saudi Arabia on March 4 and March 10, 1991. However, Khamisiyah is in Iraq (not Saudi Arabia), the 2000 DOD plume model was for March 10th only (not March 4th) and the 2000 DOD model identified about 100,000 potentially exposed GW veterans when 145,000 are reported in this report. If this group represents the 1997 and 2000 DOD plume models then this should be clearly spelled out in the text.

- 2. Regular Assessment of Data Needs. There are many potential non-VA users for this critically important VA data, with varying data needs and interests, including at least the RAC, DOD, Veteran Service Organizations (VSO's), and Congress.
 - a. Recommend that these groups be consulted annually on their data needs and that they be consulted before the next report is assembled.
- b. Recommend current proposal to provide updated data annually be implemented and maintained in perpetuity.

Recommendations

- 3. Title of report. The title of the report has a psychological impact on the various report audiences, including Gulf War veterans. The current title incorporating the new term "Pre-9/11" fails to recognize the Gulf War, Gulf War Era, and Persian Gulf Theater of Operations Service of those it describes. Gulf War veterans have already been offended by this lack of recognition of their service.
 - a. Recommend that the report's title be changed to "1990-1991 Gulf War and Era Report, with Post Desert Storm (8/91-8/2001) Stabilization Period," which would more appropriately recognize the service of those the report describes

- **4. Executive Summary.** Include in the executive summary:
 - a. The 'big numbers' broad totals from various report sections.
 - b. Compare-and-contrast between Gulf War, Gulf War Era, deployed and non-deployed, and any areas of data that appear significant, unusual, or otherwise notable. This would also require that totals and percentages for subgroups be provided in all tables so that the comparisons can be reviewed in the body of the main report.
- **5. Costs**. Currently, the report provides costs by VISN. Recommend this section of the report also include a nationwide total. Further recommend total costs -- both cumulative and current -- be shown for all agencies listed (VBA, VHA, NCA, and Vet Centers).

Recommendations

6. Mortality Data.

- a. Recommend mortality statistics be included for all cohorts and for all categories (i.e. specific diseases, accidents etc).
- b. Recommend mortality data be provided as a cumulative total, and by 5-year time segments or by age-standardized rates and compared with similar data for 1990 -1991 non-deployed era veterans.

7. ICD-9 Codes.

- a. Recommend data analysis be conducted and the results added to the report identifying usage of VHA and VBA by ICD-9 code, particularly 8800 series (UDX) [e.g., by the top 10 ICD-9 codes]
- b. Recommend data be split out by sex.

- c. Recommend data analysis and reporting of mental health ICD-9 codes and whether they exist alone or comorbid (concurrent) with other non-mental health ICD-9 diagnoses.
- d. Recommend data be provided to show number of unique veterans for all cohorts with ICD-9's for ALS, MS, other neurological diagnoses, respiratory diagnoses, dermatological (skin) diagnoses, cancers and for the 9 new presumptive rare endemic diseases.
- 8. Claims Approval.
- a. Recommend data be included showing UDX claims approval for all cohorts.
- b. Recommend UDX data for unique veteran and total claims approved for each UDX code, including fibromyalgia, irritable bowel syndrome and chronic fatigue syndrome.

Recommendations

- c. Recommend data be included showing claims approval for all cohorts for the "9 new presumptive" rare endemic diseases.
- d. Recommend data be developed showing claims approval rates for all cohorts by specific VA Regional Offices.
- **9. Meeting specific data needs.** There is a real need for current and accurate data for researchers, government bodies and other data monitoring purposes.
- a. Recommend that a process be developed to evaluate and approve requests for specific data runs of the available data, particularly, but not necessarily limited to medical researchers, DOD, VSOs, and Congress.
- b. Recommend that a report section be added detailing the request process, the application or contact information to make a data request, and the parameters of acceptable data requests.

ANNUAL OPERATIONS PLAN DISCUSSION

2012 Committee Meeting Dates

Preliminary meeting dates include:

- January 31 February 1 in Washington
- June 18-19th in Boston
- November 5-6th in Washington