

2011 Follow-Up Survey of Gulf War Era Veterans

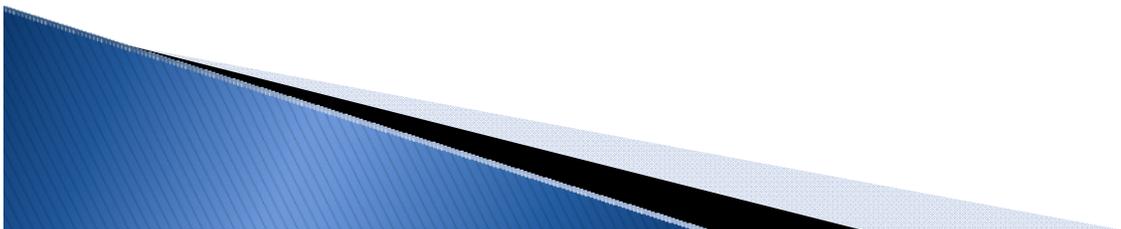


Highlights of Concerns and
Discussion Points Raised by the RAC

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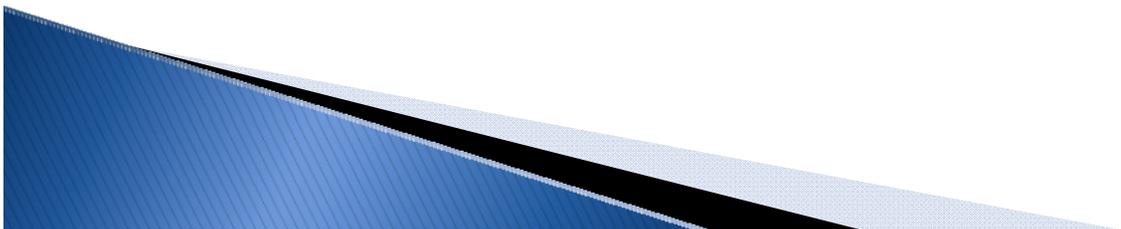
VA Follow-Up Survey: Concerns Raised by the RAC

- ▶ Members reviewed VA notice in Federal Register, survey instrument prior to last RAC meeting
- ▶ Submitted summary (2 page) written recommendations to Secretary of Veterans Affairs, OMB
- ▶ Recommended that VA suspend moving forward with current survey pending major revisions to address serious problems



Importance of the Survey

- ▶ 20 years after the war, fundamentally important questions about the health of U.S. Gulf War veterans have never been addressed, others require current information
- ▶ VA National Survey is the largest and most representative sample of U.S. Gulf War veterans
- ▶ Survey will serve as key data source for government programs for Gulf War veterans, including VA Gulf War research program



Importance of the Survey

Need answers to basic questions about the health of U.S. Gulf War veterans

- Occurrence of most diagnosed diseases unknown (overall, exposure subgroups)
- Diseases of longer latency (e.g., cancers, neuro disorders) may now be apparent
- Gulf War illness (most prevalent problem): current prevalence and long-range prognosis

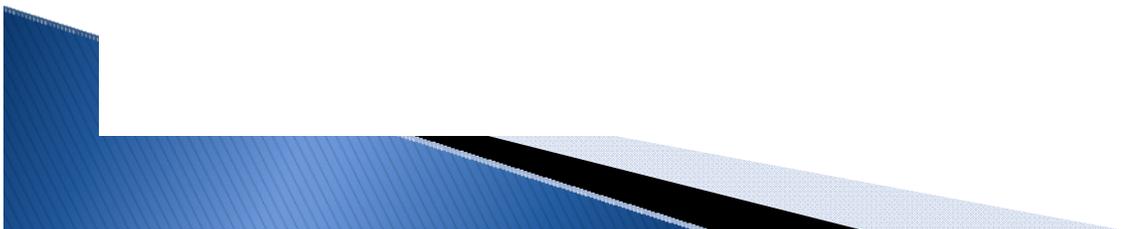
VA National Survey is the largest sample of U.S. Gulf War veterans

- Best (only?) opportunity to assess if GW veterans have excess dx diseases
- Best opportunity to determine current prevalence, expected course of GWI
- Best opportunity to identify changes in the health of Gulf War veterans over time



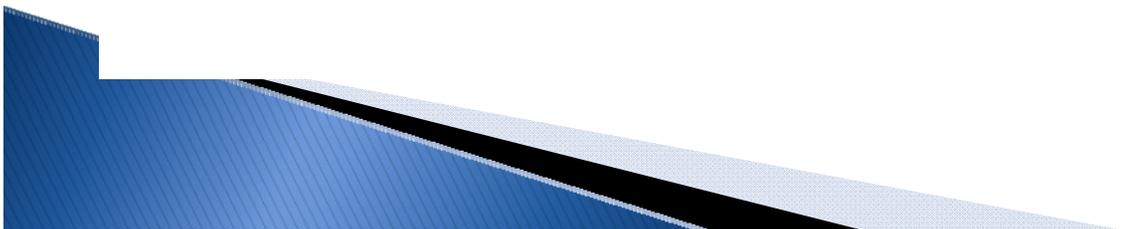
Most Important Objectives of Follow-Up Survey

- ▶ Characterize the current status of Gulf War veterans' health and changes in their health over time
 - 1) Diagnosed medical conditions
 - 2) Gulf War "undiagnosed" multisymptom illness
- ▶ Unfortunately, proposed follow-up survey does not provide adequate assessment of either



Other Areas of Importance--examples

- ▶ Assess effectiveness of medical care for GWI, treatments used by veterans for GWI
- ▶ Questions re: Health of veterans' family members
- ▶ Gulf War veterans' use of VA vs. private medical care, health insurance? economic impact of health problems?



Main Objectives: Characterize current health status of Gulf War era veterans, changes over time

1. Most prominent Gulf War problem: “undiagnosed” GWI

Assessment requires systematic inventory of symptoms. At minimum, this requires the study to:

- ▶ Systematically query symptoms known to be associated with Gulf War service (all queried in the same way)
- ▶ Query symptoms evaluated in the initial (1995) VA National Survey
- ▶ Query symptoms required to define Gulf War illness (using existing case definitions and/or to optimize a case definition)
- ▶ Provide the same basic information for each symptom (symptom severity, duration, onset)



2011 Follow-Up Survey: No Systematic Symptom Inventory

- ▶ 47-118 total symptom questions (asked in variety of ways)
 - 17 somatic symptoms: During past 4 wks, how much bothered? not/a little/a lot
 - 9 mood symptoms: how many days over past 2 wks?
 - 15 questions on anxiety attacks, panic over past 4 wks (no/yes)
 - 7 mixed symptoms (nervousness, muscle tension) how many days in last 4 wks?
 - 12 questions on anxiety/stress—how much bothered by each over past 4 wks?
- 17 symptom questions to assess PTSD
- 10 symptom questions to assess IBS
- 13 symptom questions on aspects of dyspepsia
- 8 questions similar to those for CFS (asks severity, 6 mos duration)
- 10 WOMEN ONLY questions (menstrual cycle, use of hormones, PMS)



2011 Follow-Up Survey: No Systematic Symptom Inventory

► Overall, the proposed survey

- Asks about many symptoms in many ways
- Omits key symptoms associated with Gulf War service
- Lacks info on symptom duration (can't assess chronic vs. short-term symptoms)
- Lacks info on symptom severity
- Does not allow ascertainment of any GWI case definition (e.g. only 3 of 10 CDC CMI symptoms queried)



Main Objectives: Characterize current health status of Gulf War era veterans, changes over time

2. Diagnosed medical conditions

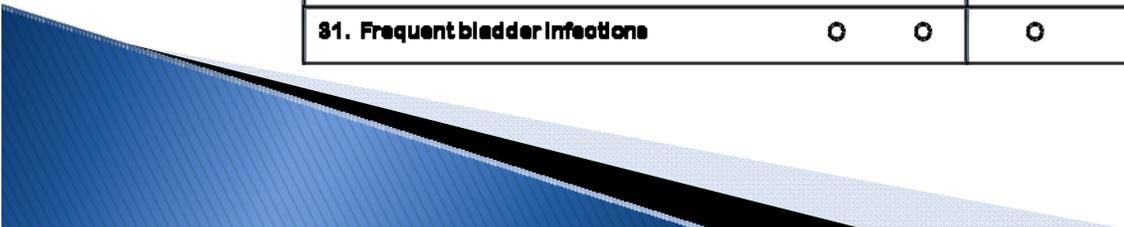
Follow up previous indications of problems; Flag any condition that potentially affects Gulf War veterans at excess rates

- ▶ Neurological diseases (e.g., MS, brain cancers, migraines, PD, difficult-to-characterize neuro diseases)
- ▶ Diagnosed cancers (identify specific types)
- ▶ Cardiovascular disease (identify specific types)
- ▶ Skin conditions (identify specific types)
- ▶ Autoimmune conditions



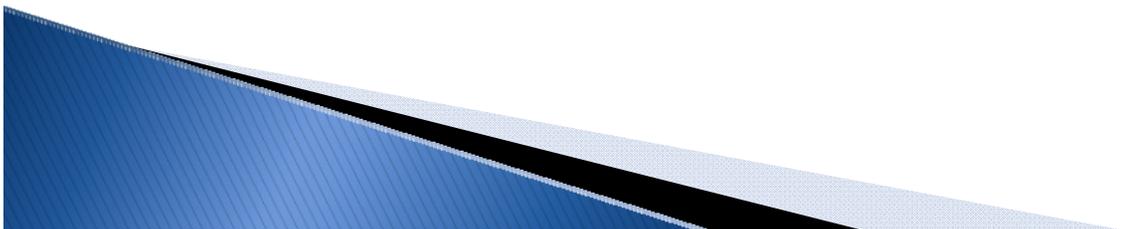
Initial (1995) Survey: Dx Medical Conditions (31)

During the past 12 months, did you have any of the following conditions?			IF YES, did you first have the problem BEFORE, DURING, or AFTER the WAR?			In what month/year did it begin?
	NO	YES	BEFORE	DURING	AFTER	MONTH/YEAR
1. Arthritis of any kind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
2. Lumbago (back disorder)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
3. Diseases of the muscles or tendons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
4. Skin cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
5. Any other cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
6. Eczema or psoriasis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
7. Dermatitis or any other skin trouble	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
8. Disease of hair or scalp, hair loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
9. Cirrhosis of the liver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
10. Hepatitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
....						
20. Migraines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___
...						
31. Frequent bladder infections	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___/___



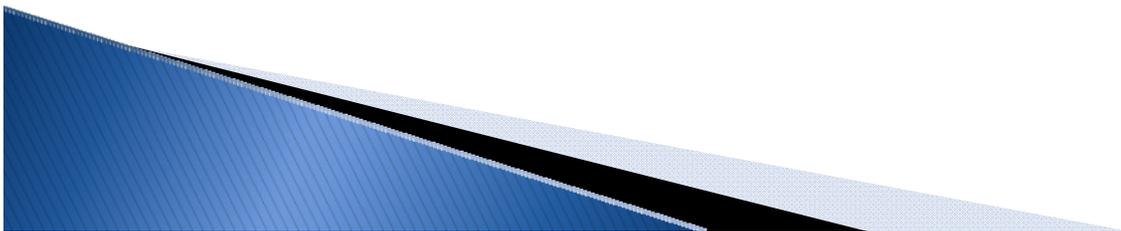
2011 Follow-Up Survey: No Systematic Assessment of Diagnosed Diseases

- ▶ Asks about 23 diagnosed medical conditions/categories (e.g., IBS, diabetes, depression, skin cancer)
- ▶ Asks about ALS and asthma, but not other conditions of concern for GW veterans (e.g. MS, brain cancers, migraines, PD, autoimmune conditions)
- ▶ Asks about general categories, rather than specific dx (e.g. “any cancer”, “arthritis of any kind” , “other endocrine disorder”)



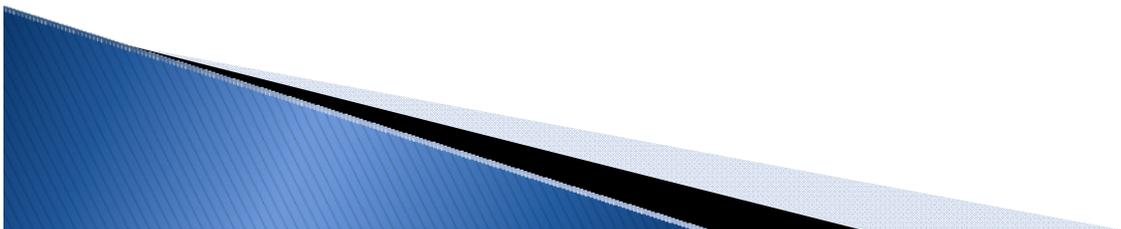
Proposed Follow-up Survey Requires Extensive Revisions to Address High Priority Issues

- ▶ Lacks usable assessment of highest priority Gulf War health issues
- ▶ Collects more extensive data on issues of lesser concern



Overall, survey content appears to reflect

- ▶ Lack of familiarity with the pressing health questions associated with Gulf War military service
- ▶ Lack of familiarity with methods for systematic assessment of multisymptom illness in population studies



Context of Larger VA Gulf War Research Program

- ▶ Concerns re: proposed survey; not clear what approval process included, whether it was reviewed by other sectors of GW research effort at VA
- ▶ Importance of comprehensive, coordinated program of Gulf War research at VA
- ▶ Will hear today about the components of a coordinated Gulf War research plan designed to achieve defined priority objectives.
- ▶ Gulf War health issues are complex, requires involvement of scientists with expertise in specific disciplines (e.g., neurology, epidemiology, toxicology)
- ▶ Program development and guidance by scientists with specific expertise in what we have learned about the health of Gulf War veterans over the past 20 years





Preliminary Indications of Diagnosed Diseases Affecting Gulf War Veterans at Excess Rates

- ▶ Increased hospitalizations for cardiac dysrhythmias, fibromyalgia, digestive diseases, respiratory diseases, injuries
- ▶ Increased brain cancer mortality in Khamisiyah-exposed
- ▶ Increased mortality from GI diseases in females
- ▶ 3x increase in “any cancer diagnosis” in Khamisiyah-exposed
- ▶ Increased asthma in oil fire smoke-exposed GW veterans
- ▶ Increased lung cancer in Gulf War veterans (state tumor registries)
- ▶ Earlier indications of increased rates of other cancers (brain, testicular)
- ▶ Epi surveys: increased rates of other diagnoses (e.g., migraines, seizures, digestive disorders, skin disorders)
- ▶ Limited/anecdotal reports of excess rates of MS, PD, autoimmune conditions