



## Gulf War Follow-Up Study 2011-2012

### **Questionnaires (mail, online):**

Topics covered in Questionnaires include:

- Behavioral factors influencing illness and injury
  - tobacco use
  - alcohol consumption
  - alcohol-impaired driving
  - physical activity
  - risky sexual behavior



## Gulf War Follow-Up Study 2011-2012

### **Questionnaires (mail, online):**

Topics covered in Questionnaires include:

- Other symptoms and health conditions
- Womens' health topics
- Height and weight
- Sexually transmitted diseases
- Demographic characteristics, including education



## Gulf War Follow-Up Study 2011-2012

Table 4. Sources of data

Research Objective	Mail, online, telephone questionnaires: origins of some (not all) questions					Review of Civilian Medical Records	Review of VA Hosp / Outpt Computer & Medical Data	VA C&P File <sup>4</sup>
	BIRLS FRC NDI <sup>1</sup>	Natn'l Hlth Survey Q <sup>2</sup>	PHQ <sup>3</sup>	PTSD 17-item checklist	SF-12			
A.1. Mortality	✓							
A.2. Health Care Utilization		✓				✓	✓	
A.3. Chronic Medical Conditions		✓				✓	✓	
A.4. Current PTSD				✓		✓	✓	
A.5. General Health		✓	✓		✓	✓	✓	
A.6. VA Disability Compensation								✓

Data are also being collected for the following potential major confounding variables: socio-demographic characteristics, weight, height, body habitus, and cigarette and alcohol consumption.

<sup>1</sup> BIRLS = Beneficiary Identification Records Locator Subsystem; FRS = Federal Records Center; NDI = National Death Index

<sup>2</sup> National Health Survey Questionnaire

<sup>3</sup> Patient Health Questionnaire: alcohol abuse/dependence, depression, somatization, and anxiety disorders

<sup>4</sup> VA Compensation and Pension File



## Gulf War Follow-Up Study 2011-2012

### Relevance:

The Gulf War Follow-Up Study will allow VA to:

- Improve the understanding of the long-term consequences of military deployment.
- Improve the understanding of the natural history of chronic conditions such as CFS-like illness and unexplained MSI.
- Plan and provide better health care for Veterans.

# 2011 Follow-Up Survey of Gulf War Era Veterans



Highlights of Concerns and  
Discussion Points Raised by the RAC

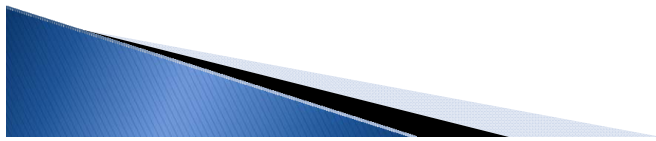
Lea Steele, Ph.D.  
Baylor University Institute  
of Biomedical Studies

## 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



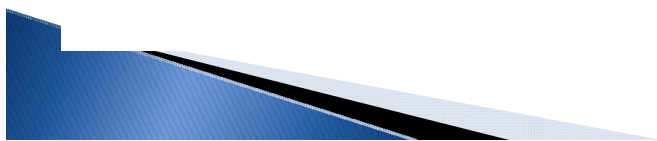
## Most Important Objectives of Follow-Up Survey

- ▶ 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?





## 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**

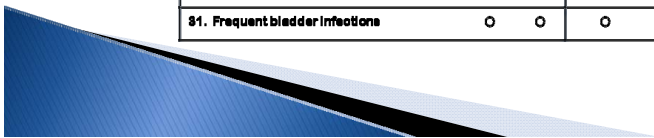
Follow up previous indications of problems; Flag any condition that potentially affects Gulf War veterans at excess rates

- ▶ 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)**

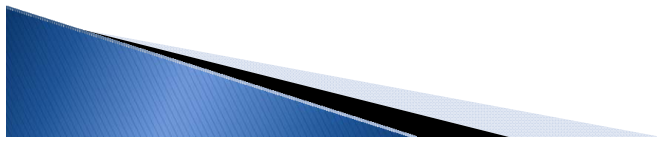
During the past 12 months, did you have any of the following conditions?			IF YES, did you first have the problem BEFORE, DURING, or AFTER the WAR?			In what month/year did it begin?
	NO	YES	BEFORE	DURING	AFTER	MONTH/YEAR
1. Arthritis of any kind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<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"/>	___/___





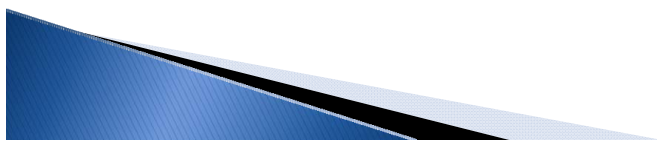
## 2011 Follow-Up Survey: No Systematic Assessment of Diagnosed Diseases

- ▶ 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")



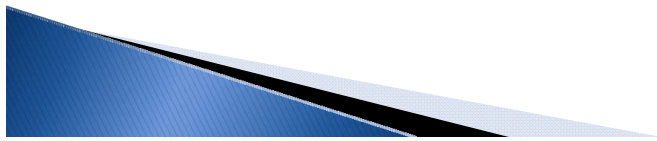
## Proposed Follow-up Survey Requires Extensive Revisions to Address High Priority Issues

- ▶ 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