

Post Deployment Health Services Environmental Health Registries – Today and the Future

Peter D. Rumm MD, MPH

Director, Pre-9/11 Era Environmental Health Programs
Post Deployment Health Service
Veterans Health Administration
202-461-1017

PDHS REGISTRIES

- Agent Orange (AOR)
- Gulf War Registry (GWR)
- Ionizing Radiation Registry (IRR)
- Toxic Embedded Fragments (TEF)
- Depleted Uranium (DU)
- Airborne Hazards / Open Burn Pit (AHOBPR)
- The future ILER



REASONS FOR REGISTRIES

- A VA Environmental Health Registry evaluation is a free, voluntary medical assessment for Veterans who may have been exposed to certain environmental hazards during military service
- Evaluations alert Veterans to possible long-term health problems that may be related to exposure to specific environmental hazards during their military service
- The registry data may help VA understand and respond to these health problems more effectively and may be useful for research purposes.
 - See also:
 https://www.publichealth.va.gov/exposures/benefits/registry-evaluation.asp
- Registries have actual and potential limitations that must be considered



AGENT ORANGE REGISTRY

Background: Agent Orange Registry was created in 1991 in response to Public Law No: 102-4, 38 USC. 527, 38 USC 1116
 PL 102-585 Section 703, and PL 100-687.



- Size: 680,000 enrolled
- Exam: General Health and considers presumptive diseases
- Eligibility: includes Vietnam, Korean DMZ at certain times, and certain Thai bases and certain occupational series, certain C-123 crew, does not include most Blue Water Navy. https://www.publichealth.va.gov/exposures/agentorange/locations/index.asp
- **Directive:** VHA Directive 1302, Agent Orange Health Registry http://vaww.va.gov/vhapublications/ViewPublication.asp?pub_ID=4303
- More information:
 https://www.publichealth.va.gov/exposures/agentorange/benefits/registry-exam.asp



GULF WAR REGISTRY

 Background: Registry created under the authority of: Public Laws 102-585, 103-446 and Title 38 United States Code (U.S.C.) 1117



- Size: 170,000 Veterans enrolled, 8,300 had Phase II exam.
- Exam Can be repeated with new information or symptoms.
- **Eligibility**: Veterans who served in the Gulf during Operation Desert Shield, Operation Desert Storm, Operation Iraqi Freedom, or Operation New Dawn are eligible for the Gulf War Registry exam.
- **Directive:** Directive 1325 Gulf War Registry.
- https://www.va.gov/vhapublications/ViewPublication.asp?pub_ID=5416
- More Information:
 https://www.publichealth.va.gov/exposures/gulfwar/benefits/registry-exam.asp



Examples of GWR Based Research

- Smith et al, 2004. The Postwar Hospitalization Experience of Gulf War Veterans Participating in U.S. Health Registries. JOEM
- Miller et al, 2006. Patterns of Health Care Seeking of Gulf War Registry Members Prior to Deployment. Military Medicine
- Brewer et al, 2007. The Symmetry Rule: a Seven-Year Study of Symptoms and Explanatory Labels among Gulf War Veterans. Risk Analysis
- Hyams et al, 2002. DoD/VA Collaboration: Combined Analysis of the VA and DoD Gulf War Clinical Registries: A Study of Clinical Findings from Systematic Medical Examinations of 100,000 U.S. Gulf War Veterans.
 (Report) https://gulflink.health.mil/combined_analysis/index.htm
- Davidson et al. Research Examining GWI in our Nation's Servicemembers.
 The study is currently recruiting subjects in the GWR through mailed
 invitations and is being conducted at the Waco, VA's Center of Excellence
 for Research on Returning War Veterans.
- Greenberg et al, 2017 Developing a Problem-Solving Treatment for Gulf War Illness: Cognitive Rehabilitation of Veterans with Complex Post-Deployment Health Concerns. Clinical Social Work Journal.

GULF WAR NEWSLETTER

INFORMATION FOR VETERANS WHO SERVED IN OPERATIONS DESERT SH AND DESERT STORM AND THEIR FAMILIES

INDEPENDENT COMMITTEE TO REVIEW INTERGENERATIONAL EFFECTS OF



IN THIS

- 1 Comm
- 3 Fibror
- Resear
- Gulf W
- 6 Burn F

8.50 × 11.00 in















🏡 🔁 https://www.ncbi.nlm.nih.... 🐞 https://www.hsdl 🌘 http://militarymedicinc.a... 😛 http://pubs.acs.org.doi.p... 💆 Web Slice Gallery 🕶













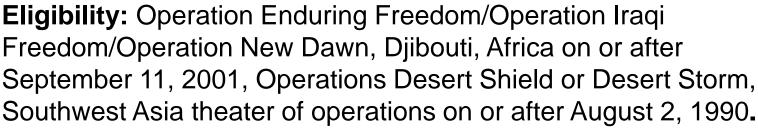
AIRBORNE HAZARDS / OPEN BURN PIT

Background: Registry created at the

Direction of by Congress

This is an online questionnaire and allows

eligible Veterans and Service Members to document their exposures and report health concerns.



Note: Includes GWR eligible Veterans

Size: About 133,000

Exam: Optional, VA is working on increasing participation rate.

Directive: Pending

More information:

https://www.publichealth.va.gov/exposures/burnpits/registry.asp



IONIZING RADIATION REGISTRY

 Background: Registry created under the authority of 38 U.S.C. 527, 38 U.S.C. 1116, PL 102-585 Section 703, and Pub. L. 100-687.



- Size: About 18,000 enrolled
- Exam: Comprehensive health exam includes an exposure and medical history, laboratory tests, and a physical exam.
- Eligibility: rules are complex including around above and below (some) grounds nuclear bomb test, POWs in Japan, found at: https://www.publichealth.va.gov/exposures/radiation/benefits/registry-exam.asp
- Directive: VHA Directive 1301, Ionizing Radiation Registry Program can be found by clicking on the following link: http://vaww.va.gov/vhapublications/ViewPublication.asp?pub_ID=5370



TOXIC EMBEDDED FRAGMENTS

Background: Established in 2008 to provide active medical surveillance for Iraq / Afghanistan Veterans with retained embedded fragments.

Size: About 17,000

Exam: Medical surveillance which can include urine metal testing, completion of an exposure questionnaire, imaging of fragments and fragment analyses.

Eligibility: Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) Veterans with Embedded Fragments

Directive: 1301.01. Screening and Evaluation Protocol for Veterans with Embedded Fragments Who Served in Iraq and/or Afghanistan Post-September 11, 2001

More Information:

https://www.publichealth.va.gov/exposures/toxic_fragments/index.asp



DEPLETED URANIUM

- Background: Created under the authority of Title 38 USC 7301(b), PL 102-585, 703(b) (2)
- Size: About 5,300
 - Registry Veterans receive a urine screen and exposure questionnaire
 - 5 positive for a DU isotopic signature
- Exam: Determination of urine uranium concentrations and completion of exposure questionnaire
- **Eligibility:** Veterans who served in the Gulf War, Bosnia, OEF, OIF, or OND may be eligible.
- Directive: VHA 1303: Evaluation Protocol For Veterans With Potential Exposure To Depleted Uranium (DU).
- More information: https://www.publichealth.va.gov/exposures/depleted_uranium/





ILER - THE FUTURE

- Individual Longitudinal Exposure Record (ILER)
 - DOD and VA are creating a record for each Service Member. This will provide a real time, long-term exposure record matched to health status and health history of Active Duty and Veterans.
 - Pilot to be delivered in Fall 2018
- ILER matches a Service Member to a:
 - Place
 - Time
 - Location
 - Event
- Transfers the record to VA on retirement or termination of Service



Benefits of ILER Operational Capabilities

- Provide context-specific exposure-related data for all available Occupational / Toxic Environmental and Chemical, Biological, Radiological, Nuclear and Explosive (CBRNE) exposures
- Reduce administrative complexity of obtaining exposure-related data
- Increase the quality of healthcare through improved and timely diagnosis and treatment
- Relieve individuals of the burden to prove they experienced harmful exposures
- Provide real time access to exposure data thereby expediting the timeliness and accuracy of claims processing and benefits determinations
- Reduce the "presumptions of exposure" by Congress.
- Provide a foundation for developing a single exposure registry
- Enable exposed cohorts to be longitudinally followed for long-term or latent health effects that could be attributable to exposures
- Increase transparency, and enhance exposure-related communication with individuals, groups, and other stakeholders (e.g. Congress, Veterans Service Organizations (VSOs))
- Link individuals to exposure events



Training Conference

- PDHS will sponsor a funded training conference for coordinators and lead clinicians in St. Louis from July 9-13.
- Topics will include various exposures with several lectures relating to Gulf War or related topics. There will also be several interactive sessions.
- VISN leads will attend and 4-6 from VISNs with priority to those who were in focus groups or the HAIG survey development.
- Plan to invite those unable attend to future training conferences.



Recently Updated Information

- http://vaww.publichealth.va.gov/exposures/health_c oordinators.asp
- http://vaww.publichealth.va.gov/exposures/health_c linicians.asp
- https://www.publichealth.va.gov/exposures/coordin ators.asp

Various resources for coordinators and clinicians.



Environmental Health Registries Part 2 and Gulf War Research Update

Aaron Schneiderman, PhD, MPH, RN

Director, Post Deployment Health Service Epidemiology

Veterans Health Administration



EXPOSURE REGISTRIES

Strengths

- Can be a valuable tool for surveillance and epidemiology
 - Can be used for research, but must recognize the limitations
- May collect information on occupational exposure and disease in large populations
- May provide an overview of some disease trends
- A registry exam is not a disability/compensation exam, but this information goes into Veteran's medical record.

Weaknesses

- Significant inherent limitations in the use of registries to draw inferences regarding the presence or strength of an association between an exposure and a health outcome* (Critical research issue)
 - Issues include:
 - Self-reporting of an effect
 - Misclassification
 - Recall Bias
 - Self-selection
 - Missing data
 - Large populations: Studies may lead to statistically significant but not clinically significant results
 - Cost, maintenance of data and security issues.

^{*}National Academies Press: Assessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry. 2017



CHALLENGES AND OPPORTUNITIES

- Imperative to realize the value of exposure registries
- Bright line between AH&OBPR and everything that came before
 - Web-based enhances Veteran access
 - Data are more readily available for end users
 - NJ WRIISC CoE is actively engaged in applying data in applicable investigations
 - Platform allows expansion to gather additional information (Qarmat Ali)



CHALLENGES AND OPPORTUNITIES

- Current activity with registries geared towards
 - Data cleaning
 - Developing analytic data sets
 - Developing file documentation
 - Assess and document data strengths and weaknesses
 - Produce analytic products and reports
 - Assess development of analytic files for end users



GULF WAR EPIDEMIOLOGY RESEARCH UPDATE

- Gulf War Follow-up Study (GWFS)
 - Manuscripts accepted/in press
 - Gulf War Illness at baseline survey (1995) using the CDC and Kansas definitions
 - GW era cohort comparison: Millennium Cohort (MilCo) and VA GWFS



GULF WAR EPIDEMIOLOGY RESEARCH UPDATE

- Gulf War Follow-up Study (GWFS)
 - Other work underway
 - Gender stratified analysis of health outcomes
 - Re-entry of the 2005 survey data is scheduled for completion mid-summer
 - Developing plan for checking these data and developing longitudinal database from 3 surveys
- CMI prevalence over time in MilCo panel of GW (deployed, nondeployed and other non contemporaneous sample) (Dursa Porter et al)

POST DEPLOYMENT HEALTH SERVICES REGISTRIES

Questions?