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

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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](https://www.publichealth.va.gov/exposures/agentorange/locations/index.asp)
• **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.


• **More Information:**
Examples of GWR Based Research


• Miller et al, 2006. *Patterns of Health Care Seeking of Gulf War Registry Members Prior to Deployment*. Military Medicine


• 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.

GULF WAR NEWSLETTER
INFORMATION FOR VETERANS WHO SERVED IN OPERATIONS DESERT SHIELD AND DESERT STORM AND THEIR FAMILIES

INDEPENDENT COMMITTEE TO REVIEW INTERGENERATIONAL EFFECTS OF GULF WAR

IN THIS ISSUE
1. Community
3. Fibromyalgia
6. Burn Pits
5. Gulf War Illness
3. Research
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

• **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
**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

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/](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_clinicians.asp](http://vaww.publichealth.va.gov/exposures/health_clinicians.asp)
- [https://www.publichealth.va.gov/exposures/coordinators.asp](https://www.publichealth.va.gov/exposures/coordinators.asp)

Various resources for coordinators and clinicians.
Environmental Health Registries Part 2 and Gulf War Research Update

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• **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)
• 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 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 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)
Questions?