93VA131

SYSTEM NAME:
Gulf War Registry-VA.

SYSTEM LOCATION:
Character-based data from Gulf War Registry Code Sheets are maintained in a registry dataset at the Austin Automation Center (AAC), 1615 Woodward Street, Austin, Texas 78772. Since the dataset at the AAC is not all-inclusive, i.e., narratives, signatures, noted on the code sheets are not entered into this system, images of the code sheets are maintained at the Department of Veterans Affairs (VA), Environmental Agents Service (131), 810 Vermont Avenue, NW., Washington, DC 20420. These are electronic images of paper records, i.e., code sheets and questionnaires that are stored on optical disks. With the transition to a web-based data entry system, this optical disk system will be discontinued in 2004. Images of code sheets are accessible in the web-based data entry system.

CATEGORIES OF INDIVIDUALS COVERED BY THIS SYSTEM:
Veterans who may have been exposed to toxic substances or environmental hazard while serving in the Southwest theatre of operations during the Gulf War from August 2, 1990, until such time as Congress by law ends the Gulf War, and have had a Gulf War Registry (GWR) examination at a VA medical facility. Also, a spouse or child suffering from an illness or disorder (including birth defects, miscarriages, or stillbirth), which cannot be disassociated from the veteran's service in the Southwest Asia theatre of operations and who has had a GWR examination performed by a VA or non-VA clinician.

CATEGORIES OF RECORDS IN THE SYSTEM:
These records consist of code sheet records recording VA facility code identifier where veteran was examined or treated; veteran's name; address; social security number; date of birth; race/ethnicity; marital status; sex; branch of service; periods of service; hospital status, i.e., inpatient; outpatient; areas of service in the Gulf War theatre of operations; list of military units where veteran served; military occupation specialty; names of units in which veteran served; veteran's reported exposure to environmental factors; any traumatic experiences while in the Gulf War; veteran's self-assessment of health; veteran's functional
impairment; report of birth defects and infant death(s) among veteran's children and/or problems with pregnancy and infertility; date of registry examination; veteran's complaints/symptoms; consultations; diagnoses; disposition (hospitalized, referred for outpatient treatment, etc.); whether veteran had an unexplained illness and had further tests and consultations and diagnoses as part of a Phase II, Uniform Case Assessment Examination; and name and signature of examiner/clinician coordinator, when provided. Similar responses for spouse and children of Gulf War veterans examined by non-VA physicians are contained in the records.

Another category of data entries is obtained from depleted uranium (DU) questionnaires, a supplement to the Gulf War code sheet. The data entries may contain the facility identifier where the information was completed; demographic information (name and social security number); daytime and evening phone numbers; date of questionnaire completion; date of arrival in and departure from the Gulf War theatre of operations; source of referral to VA medical center for evaluation; where veteran served (i.e., Iraq, Kuwait, Saudi Arabia, the neutral zone [between Iraq and Saudi Arabia], Bahrain, Qatar, the United Arab Emirates, Oman, Gulf of Aden, Gulf of Oman and the Waters of the Persian Gulf, Arabian Sea and Red Sea); capacity in which veteran served; questions relating to potential inhalation exposures to DU including those on, in, or near vehicles hit with friendly fire or enemy fire, entering burning vehicles, individuals near fires involving DU munitions, individuals salvaging damaged vehicles, and those near burning vehicles; whether veteran was wounded, retained DU fragments in veteran's body, handled DU penetrator rounds or any other exposures to DU; whether a 24-hour urine collection for uranium was performed; name, title and signature of examiner/environmental health clinician, when provided, and results of urine uranium tests, expressed per microgram per gram creatinine.

AUTHORITY FOR MAINTENANCE OF THE SYSTEM:

Title 38, United States Code (U.S.C.) 1710(e)(1)(B) and § 1720E.

PURPOSE(S):

The records will be used for the purpose of providing information about: Veterans who have had a GWR examination at a VA facility and their spouses and/or children who have had examinations by VA or non-VA clinicians to assist in generating hypotheses for research studies; providing management with the capability to track patient demographics; reporting birth defects among veterans' children and grandchildren; planning the delivery of health care services and associated cost; and assisting in the adjudication of claims possibly related to exposure to a toxic substance or environmental hazard.

ROUTINE USES OF RECORDS MAINTAINED IN THE SYSTEM, INCLUDING CATEGORIES OF USERS AND THE PURPOSES OF SUCH USES:

VA may disclose protected health information pursuant to the following routine uses where required by law, or required or permitted by 45 CFR parts 160 and 164.
1. The record of an individual who is covered by this system may be disclosed to a member of Congress or staff person acting for the member when the member or staff person requests the record on behalf of, and at the written request of, that individual.

2. Disclosure of records covered by this system, as deemed necessary and proper to named individuals serving as accredited service organization representatives, and other individuals named as approved agents or attorneys for a documented purpose and period of time, to aid beneficiaries in the preparation and presentation of their cases during the verification and/or due process procedures, and in the presentation and prosecution of claims under laws administered by VA.

3. A record containing the name(s) and address(es) of present or former members of the armed services and/or their dependents may be released from this system of records under certain circumstances:
   a. To any nonprofit organization if the release is directly connected with the conduct of programs and the utilization of benefits under Title 38, and
   b. To any criminal or civil law enforcement governmental agency or instrumentality charged under applicable law with the protection of the public health or safety if a qualified representative of such organization, agency or instrumentality has made a written request that such name(s) or address(es) be provided for a purpose authorized by law; provided, further, that the record(s) will not be used for any purpose other than that stated in the request and that the organization, agency or instrumentality is aware of the penalty provision of 38 U.S.C. 5701(f).

4. Disclosure may be made to the National Archives and Record Administration (NARA) in records management inspections conducted under authority of Title 44 United States Code.

5. Disclosure of information, excluding name and address (unless name and address is furnished by the requestor) for research purposes determined to be necessary and proper, to epidemiological and other research facilities approved by the Under Secretary for Health.

6. In order to conduct Federal research necessary to accomplish a statutory purpose of an agency, at the written request of the head of the agency, or designee of the head of that agency, the name(s) and address(es) of present or former personnel or the Armed Services and/or their dependents may be disclosed
   a. to a Federal department or agency, or
   b. directly to a contractor of a Federal department or agency. When a disclosure of this information is to be made directly to the contractor, VA may impose applicable conditions on the department, agency, and/or contractor to ensure the appropriateness of the disclosure to the contractor.

7. VA may disclose on its own initiative any information in this system, except the names and home addresses of veterans and their dependents, which is relevant to a suspected or reasonably imminent violation of law, whether civil, criminal or regulatory in nature and whether arising by general or program statute or by regulation, rule or order issued pursuant
thereto, to a Federal, state, local, tribal, or foreign agency charged with the responsibility of investigating or prosecuting such violation, or charged with enforcing or implementing the statute, regulation, rule or order. On its own initiative, VA may also disclose the names and addresses of veterans and their dependents to a Federal agency charged with the responsibility of investigating or prosecuting civil, criminal or regulatory violations of law, or charged with enforcing or implementing the statute, regulation, rule or order issued pursuant thereto.

8. For program review purposes and the seeking of accreditation and/or certification, disclosure may be made to survey teams of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), College of American Pathologists, American Association of Blood Banks, and similar national accreditation agencies or boards with whom VA has a contract or agreement to conduct such reviews but only to the extent that the information is necessary and relevant to the review.

9. Records from this system of records may be disclosed to the Department of Justice (DOJ) or in a proceeding before a court, adjudicative body, or other administrative body before which the Department is authorized to appear when: (a) The Department, or any component thereof; or (b) any employee of the Department in his or her official capacity where the DOJ or the Department has agreed to represent the employee; or (c) the U.S., when the Department determines that litigation is likely to affect the Department or any of its components; is a party to litigation, and has an interest in such litigation, and the use of such records by the DOJ or the Department is deemed by the Department to be relevant and necessary to the litigation provided, however, that the disclosure is compatible with the purpose for which the records were collected.

10. Relevant information may be disclosed to individuals, organizations, private or public agencies, etc., with whom VA has a contract or agreement to perform such services as VA may deem practical for the purposes of laws administered by VA, in order for the contractor to perform the services of the contract or agreement.

11. Disclosure to other Federal agencies may be made to assist such agencies in preventing and detecting possible fraud or abuse by individuals in their operations and programs.

12. VA may, on its own initiative, disclose any information or records to appropriate agencies, entities, and persons when (1) VA suspects or has confirmed that the integrity or confidentiality of information in the system of records has been compromised; (2) the Department has determined that as a result of the suspected or confirmed compromise, there is a risk of embarrassment or harm to the reputations of the record subjects, harm to economic or property interests, identity theft or fraud, or harm to the security, confidentiality, or integrity of this system or other systems or programs (whether maintained by the Department or another agency or entity) that rely upon the potentially compromised information; and (3) the disclosure is to agencies, entities, or persons whom VA determines are reasonably necessary to assist or carry out the Department's efforts to respond to the suspected or confirmed compromise and prevent, minimize, or remedy such harm. This routine use permits disclosures by the Department to respond to a suspected or confirmed
data breach, including the conduct of any risk analysis or provision of credit protection services as provided in 38 U.S.C. 5724, as the terms are defined in 38 U.S.C. 5727.

POLICIES AND PRACTICES FOR STORING, RETRIEVING, ACCESSING, RETAINING AND DISPOSING OF RECORDS IN THE SYSTEM:

STORAGE:
In 2003, the data collection process moved to a secure web-based system. Data previously recorded manually and converted to electronic format is now input through the secure VA Intranet system. Data is stored on a web server hosted by the AAC and is retrievable by the facility. Three levels of access are provided for the data that is input, using password security linked to the AAC Top Secret Security system, with mandated changes every 90 days. Data from individual facilities is uploaded nightly and stored on Direct Access Storage Devices at the AAC, Austin, Texas, and on optical disks at VA Central Office, Washington, DC. AAC stores registry tapes for disaster back up at an off-site location. VA Central Office also has back-up optical disks stored off-site. In addition to electronic data, registry reports are maintained on paper documents and microfiche.

The optical disk system is currently being utilized where there is no access to the secure web-based system. The optical disk system is scheduled to be discontinued in 2004 and all access to the GWR system will be through the secure web-based data entry system. Records will be maintained and disposed of in accordance with records disposition authority approved by the Archivist of the United States.

RETRIEVABILITY:
Records are indexed by name of veteran and social security number.

SAFEGUARDS:
Access to records at VA Central Office is only authorized to VA personnel on a “need to know” basis. Records are maintained in manned rooms during working hours. During non-working hours, there is limited access to the building with visitor control by security personnel. Registry data maintained at the AAC can only be updated by authorized AAC personnel.

Data is securely located behind the VA firewall and only accessible from the VA Local Area Network (LAN) through the VA Intranet. Read access to the data is granted through a telecommunications network to authorized VA Central Office staff. AAC reports are also accessible through a telecommunications network on a read-only basis to the owner (VA facility) of the data. Access is limited to authorized employees by individually unique access codes which are changed periodically.

Physical access to the AAC is generally restricted to AAC staff, VA Central Office staff, custodial personnel, Federal Protective Service and authorized operational personnel through electronic locking devices. All other persons gaining access to the computer rooms are escorted. Backup records stored off-site for both the AAC and VA Central Office are
safeguarded in secured storage areas. A disaster recovery plan is in place and system recovery is tested at an off-site facility in accordance with established schedules.

RETENTION AND DISPOSAL:

Records will be maintained and disposed of in accordance with records disposition authority approved by the Archivist of the United States.

SYSTEM MANAGER(S) AND ADDRESS:

Director, Environmental Agents Service (131), Office of Public Health and Environmental Hazards, (clinical issues) and Management/Program Analyst, Environmental Agents Service (131) (administrative issues), VA Central Office, 810 Vermont Avenue, NW., Washington, DC 20420.

NOTIFICATION PROCEDURE:

An individual who wishes to determine whether a record is being maintained in this system under his or her name or other personal identifier, or wants to determine the contents of such record, should submit a written request or apply in person to the last VA facility where medical care was provided or submit a written request to the Director, Environmental Agents Service (131), Office of Public Health and Environmental Hazards or the Management/Program Analyst, Environmental Agents Service (131), VA Central Office, 810 Vermont Avenue, NW., Washington, DC 20420. Inquiries should include the veteran's name, social security number, and return address.

RECORD ACCESS PROCEDURES:

An individual who seeks access to records maintained under his or her name may write or visit the nearest VA facility or write to the Director, Environmental Agents Service (131) or the Management/Program Analyst, Environmental Agents Service (131), VA Central Office, 810 Vermont Avenue, NW., Washington, DC 20420.

CONTESTING RECORDS PROCEDURES:

(See “Record Access Procedures.”)

RECORD SOURCE CATEGORIES:

VA patient medical records, various automated record systems providing clinical and managerial support to VA health care facilities, the veteran, family members, and records from the Veterans Benefits Administration, Department of Defense, Department of the Army, Department of the Air Force, Department of the Navy and other Federal agencies.