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GULF WAR VETERANS

Limitations of Available Data for Accurately Determining the Incidence of Tumors

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Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss the results of our recently completed report, at the Subcommittee's request, on the (1) reliability and utility of existing data for determining the incidence of tumors among Gulf War veterans and (2) uses of the data by the Departments of Defense (DOD) and Veterans Affairs (VA) to monitor tumors in the Gulf War veteran population.¹ Our review focused on five types of data sources: mortality data, DOD and VA hospital and outpatient medical records, DOD and VA Gulf War health registries, survey results, and national and state cancer registries. It is important to point out that most of the data sources we reviewed were not designed for medical research purposes but rather for other uses, such as the administration of records or veteran outreach. Nevertheless, researchers have used some of these data sources to assess the nature and extent of Gulf War illnesses. Our intent was to see if the data could be used to determine the frequency of tumors and to examine the appropriateness of using the data in other applications.

I will first summarize our study results. Then, I will present observations on subsequent data analysis, requested by the Subcommittee, to assess the numbers and types of tumors that are reported for Gulf War veterans in available VA health and benefits disability databases. Following this, I will provide more details on our findings.

Results in Brief

Based on our completed study, we found that none of the data sources providing information on the health of Gulf War veterans can be used to reliably estimate the incidence of tumors or other illnesses. Existing government data systems are generally limited by poor coverage of the Gulf War veteran population and problems of accuracy and completeness. As a result, it is not known how many Gulf War veterans have tumors or whether they have a higher incidence of them than other veterans. DOD and VA have begun efforts to improve these data systems but have not developed the capability to effectively link information from different sources to assess tumors or other illnesses among Gulf War veterans. DOD and VA also recently funded a few research studies that should provide additional information on tumor cases in the future. However, these studies are not the product of a systematic effort to study the incidence of tumors, and limitations to the studies will prevent them from providing reliable and valid estimates of Gulf War veterans' tumors.

¹Gulf War Veterans: Incidence of Tumors Cannot Be Reliably Determined From Available Data (GAO/NSIAD-98-89, Mar. 3, 1998).

Following completion of our report, we conducted additional work to assess the feasibility of linking data from different sources and determining the number of tumors among Gulf War veterans. Based on our analysis of only VA health and disability benefits databases, we identified about 14,700 Gulf War veterans with tumors. Although we did not conduct appropriate analyses to determine whether the total we computed translates into a higher or lower rate of cases as compared to other groups of veterans, it is a larger number of cases than that reported in other studies of Gulf War veterans. These data reflect cases that are reported in VA data systems and do not include Gulf War veterans who are still on active duty or those who use non-VA medical facilities. While we were able to merge VA data at an aggregate level to estimate the total number of tumors, detailed analysis involving the combination of cases by type of tumor will be more difficult to conduct because of different diagnostic coding systems used in the different data systems.

GAO's Review of Existing Data Sources to Determine Incidence of Tumors Among Gulf War Veterans

Background

Although casualties were relatively light during the Gulf War deployment, thousands of veterans have come forward complaining of various illnesses, including cancer, in the years following the conflict. During the Gulf War, American troops may have been exposed to several potentially hazardous substances. These include chemical warfare agents, depleted uranium from munitions, smoke from oil-well fires, infectious diseases, pesticides, petroleum fuels, and vaccines. Some of these substances have previously been associated with different types of cancer through animal laboratory studies and other epidemiological research investigations. For example, combustion products from petroleum include polyaromatic hydrocarbons, benzene, and carbon disulfide, some of which are known to cause lung cancer when inhaled. Exposure to certain pesticides has also been linked to lymphatic and lung cancers. In addition, exposure to radioactive particles has been tied to higher rates of respiratory and other

cancers. Information on exposures that took place during the Gulf War, however, has been either incomplete or nonexistent due to the lack of record-keeping and measurement before, during, and after the deployment of troops; loss of key records; poor recall by veterans; and other factors.

The development of cancer is usually characterized by a latency period of many years from initial exposure to a harmful agent to a definitive medical diagnosis. Depending on the nature and extent of the exposure, type of cancer, and characteristics of different individuals, the latency period may be as long as 30 years or more. The most common types of cancers have a latency period of 15 years or more, but in certain situations cancer can develop more quickly (e.g., in cases where the immune system is compromised).

Given that there is a lengthy latency period for most tumors, it may be too soon to detect any increase in tumors among Gulf War veterans. Also, since cancer is a relatively rare event,² large population groups may need to be observed over several years to assess incidence and determine whether it has changed over time. Furthermore, without credible exposure information, it is hard to form specific hypotheses about what kinds of tumors might grow in what individuals. Although such constraints exist, it is nonetheless important to begin monitoring Gulf War veterans to assess whether they are suffering from an increase in tumors so that appropriate health care and treatment can be provided where needed. With many types of tumors, early detection is important to more effective treatment outcomes.

Mortality Data

One source for estimating the incidence of cancer among Gulf War veterans uses mortality as an indicator. The VA maintains a large administrative database, the Beneficiary Identification and Records Locator Subsystem (BIRLS), which can be used to track the mortality of veterans. The system's strength is its broad coverage of the veteran population (estimated to be 80 to 90 percent of the deceased veteran population, according to VA and other researchers) and its cost-effectiveness for ascertaining vital status and causes of death. However, mortality is only a proxy measure for incidence because not all cancers result in death, and those that do may take several years to show up. Mortality data provide good estimates of incidence for cancers that

²The average age-adjusted incidence rate for all types of cancer combined was 400 cases per 100,000 population in the United States in 1990-91 (National Cancer Institute, *Cancer Rates and Risks*, 1996, p. 17). Among the age group that served in the Gulf War, incidence is lower (fewer than 100 cases per 100,000 population for the ages 15-44).

have a high mortality rate (such as lung and liver cancers), but they are less useful for cancers with lower rates of mortality (such as prostate and breast cancers). Because of these limitations, mortality data will systematically underreport overall cancer incidence.

In one published study using data from BIRLS, the VA assessed whether mortality from a range of diseases (including cancer) was different for Gulf War veterans compared with a sample of veterans who were not deployed to the Persian Gulf.³ The study, which covered deaths occurring in a 2-year period after the war, found that there was a small but significant excess of deaths among Gulf War veterans compared with nondeployed veterans and that the excess was due mainly to accidents and not disease. Of the 1,765 Gulf War veterans who died during the study period, 119 died from cancer, showing no statistically significant difference compared with the cancer death rate among nondeployed veterans. One key limitation of this portion of the study is the relatively short time period for assessing veterans that died from cancer.

Another limitation of the study, which the authors acknowledged, is whether the study's comparison groups were appropriately matched. Military personnel who were ill or recovering from an illness would not have been deployed to the Gulf War area. However, these personnel were included in the comparison group of nondeployed veterans. This meant that the comparison group may have been less healthy than the deployed veterans group. The extent to which a higher rate of prior illnesses among nondeployed veterans resulted in a different rate of mortality (or cancer mortality in particular) and thus biased the study findings is unknown.

VA is now updating the study, extending the period to be studied through 1995, and the results should be published later this year.

DOD and VA Medical Records

Both DOD and VA maintain an automated database containing detailed medical and demographic information on patients discharged from their respective hospitals. Both data systems contain millions of records, but they do not represent the entire active duty and veteran population. DOD's data include most hospitalizations of active duty personnel, in large part because DOD medical care is free and readily available to active duty personnel; however, some veterans' groups have reported that Gulf War veterans are seeking medical care outside DOD. VA also has an extensive

³Kang, H. K., and Bullman, T. A., "Mortality Among U.S. Veterans of the Persian Gulf War," New England Journal of Medicine, vol. 335 (1996), pp. 1498-1504.

network of medical centers across the country, but the overwhelming majority of veterans who have separated from the military use non-VA hospitals and medical facilities. A survey conducted by VA in the late 1980s, for example, estimated that only about 20 percent of veterans had ever used a VA hospital.

Another weakness of these data systems has been the lack of coverage of outpatient medical care. Coverage of outpatient care is important because more patients have been diagnosed and treated for many types of tumors in outpatient facilities in recent years. DOD currently has no centralized reporting system for its outpatient facilities, although an automated system is under development. In October 1996, VA established an automated system that includes diagnostic information, but consistent and reliable outpatient reporting may not be available for several years.

In addition to limitations in terms of population coverage, there are also issues regarding the accuracy and completeness of hospitalization data reporting. Miscoding of diagnoses has been problematic in the past, as shown by VA researchers in previous assessments of certain types of cancer among Vietnam veterans. For example, in one case-control study of over 400 Vietnam veterans identified in VA's hospitalization database as having malignant tumors of connective and other soft tissue, close to 40 percent of the records were found to be miscoded or misclassified when hospital pathology reports were subsequently collected and independently reviewed by an expert pathologist.⁴

In a large DOD-funded study published in 1997, the hospitalization experiences of all active duty Gulf War veterans during the period 1991-93 were compared with a sample of other active duty military personnel who were not deployed to the Gulf region.⁵ Overall, the authors found there was no excess in hospitalizations among Gulf War veterans compared with other military personnel. However, Gulf War veterans had higher rates of hospitalizations in certain years for mental disorders, diseases of the blood, and diseases of the genitourinary system. Hospitalization rates for tumor cases were also higher for Gulf War veterans, but the differences were not statistically significant and most involved benign conditions.

⁴Kang, H.K. et al, "Soft Tissue Sarcomas and Military Service in Vietnam: A Case Comparison Group Analysis of Hospital Patients," *Journal of Occupational Medicine*, vol. 28 (1986), pp. 1215-1218.

⁵Gray, G.C. et al, "The Postwar Hospitalization Experience of U.S. Veterans of the Persian Gulf War," *New England Journal of Medicine*, vol. 335 (1996) pp. 1505-13.

A major strength of this study is its large size and statistical power to detect differences in rates of hospitalizations between deployed and nondeployed military personnel. However, a key limitation of the study, which influences the interpretation of the results, is that it excluded hospitalizations of Gulf War veterans who separated from the services and hospitalizations of active duty personnel who used non-DOD hospitals. Another important limitation of the study is that the time frame was far too short for detecting any diseases resulting from possible exposures during the war, such as tumors, which have lengthy latency periods.

The same researchers have underway a related follow-up study to examine hospitalizations of Gulf War veterans in military and nonmilitary hospitals in California. Although the study results cannot be generalized to the entire Gulf War population, it is large and one of the first to systematically combine military and nonmilitary hospitalizations. The study period is longer (1991-95); however, the problem of detecting diseases with a lengthy latency period is still an issue, and outpatient data will be excluded.

Gulf War Health Registries

Both DOD and VA have established separate programs that provide medical examinations and diagnostic services, free of charge, to Gulf War veterans. The VA began its Persian Gulf Health Registry Examination Program in 1992, and DOD started its Comprehensive Clinical Evaluation Program in 1994. An existing health problem is not necessary for participation in the programs; any Gulf War veteran with health questions or concerns is eligible to enroll on a voluntary basis. Close to 100,000 veterans have completed either the VA or DOD registry examination. Of that number, less than 1 percent of veterans have received a primary diagnosis of a malignant or benign tumor.

The suitability of the registries for assessing cancer incidence is extremely limited. As designed, the registries are not intended to be used to determine the frequency and causes of illnesses among the general Gulf War veteran population, but rather to diagnose and treat voluntary participants' symptoms. Because the participants were not selected based on a random sample, there is no way to know whether their health problems are similar to those of the general population of Gulf War veterans. In addition, because there is no ready comparison or control group for the registry participants, the significance of the data reported cannot be determined. A further limitation of the registry data is that they capture information about the health of veterans only at one point in time.

Thus, if a veteran develops cancer or another illness later on, the registry data will not reflect this.

Data quality concerns also have been raised in a previous review of the VA registry by the Institute of Medicine. The Institute found, for example, that there was a considerable delay between the collection of the examination data and their entry into the registry database.⁶ We also found that VA medical facilities have not reported registry examination information consistently. It appears that a large number of case records submitted for input into the registry database have been returned to the medical facilities due to coding errors. At the same time, effective quality assurance procedures have not been in place to ensure that rejected records are corrected and reentered into the database. Thus, data coverage even for those who participate in the registries may be incomplete.

Survey Data

Another data approach involves developing information about the incidence of tumors using survey methods such as a questionnaire administered to a sample of veterans. Significant advantages to using the survey approach include the ability to draw a random sample of Gulf War veterans and an appropriate comparison group. A survey also permits researchers to gather other information, such as information about exposures and family history, that might shed light on the causes of a disease. Limitations of this approach include the possibility of response bias (individuals who complete the survey not being representative of the sample as a whole) and the subjectivity of self-assessments. The extent to which response bias is a factor, however, can be estimated through a special survey of nonrespondents, which may be conducted by telephone or personal interviews. The results of the nonrespondent survey can then be compared to the results of the principal survey to gauge the degree to which respondents are typical of the overall sample. Subjectivity of the assessments of cancer or other illnesses can also be gauged to a degree through an independent medical review of a subsample of respondents. A further concern in implementing large population surveys is that they tend to be much more costly than the other approaches. In addition, the type and number of questions must be restricted, or the response rate will be low.

⁶Institute of Medicine, *Health Consequences of Service During the Persian Gulf War: Initial Findings and Recommendations for Immediate Action*, 1995.

VA is currently using a survey approach to study the general health status of Gulf War veterans. The National Health Survey of Persian Gulf War Era Veterans was mailed to a random sample of 15,000 Gulf War and 15,000 nondeployed veterans. The questionnaire includes a checklist of illnesses, including skin cancer and "any other cancer," and a checklist of symptoms such as "coughing" and "skin rashes." In addition to questions about current health status, respondents were also asked to report about their exposure to a list of agents, including nerve gas, depleted uranium, and smoke from oil-well fires, while they were in the Gulf War region. The overall response rate to the survey has been relatively low (57 percent). VA is conducting a survey of nonrespondents in order to evaluate nonresponse bias. VA is also addressing the limitation imposed by subjective assessments through an independent review of medical records and the "comprehensive physical examination" of a subsample of 2,000 respondents (1,000 in each of the Gulf War veteran and nondeployed veterans groups). The sample size of the VA survey, however, may be too small to identify an elevated incidence of most cancers. VA has acknowledged this possible limitation.

A population-based survey to assess the prevalence of self-reported symptoms and illnesses among Gulf War veterans was also conducted in Iowa from September 1995 through May 1996.⁷ By telephone, a random sample of about 3,700 Gulf War and non-Gulf War veterans from Iowa were surveyed. Overall, the study found that Gulf War veterans reported a significantly higher prevalence of a wide range of medical and psychiatric conditions compared with military personnel who were not deployed to the Gulf War. The primary conditions on which differences were reported included depression, posttraumatic stress syndrome, chronic fatigue, cognitive dysfunction, and respiratory diseases. The rate of cancer reported among these Gulf War veterans was generally low (an estimated rate of about 1 per 100 subjects), but it was slightly higher than that of the comparison group.

Cancer Registries

Another source for estimating the incidence of cancer is population-based cancer registries that compile standardized reports of cancer cases directly from medical facilities (typically hospitals) on an ongoing basis. A national cancer registry (the Surveillance, Epidemiology, and End Results (SEER)) established by the National Cancer Institute reports incidence rates for the general population and key subgroups but cannot be used to

⁷The Iowa Persian Gulf Study Group, "Self-Reported Illness and Health Status Among Gulf War Veterans," *Journal of the American Medical Association*, 277 (1997), pp. 238-245.

identify the Gulf War population. Many available state registries could be used to identify Gulf War veterans, but the registries vary in terms of data quality and reporting consistency and coverage. For example, many states require only hospitals to report on cancers and do not capture cases diagnosed by private physicians, laboratories, and health maintenance organizations.

The VA has provided initial funding for a study to assess cancer incidence among Gulf War veterans in New England, based on cases reported in the state cancer registries in the region. Cases will be identified by matching the registries against a roster of all veterans who were deployed to the Gulf War conflict. The first phase of the study has been funded to develop a framework for merging data from the individual state registries. The next phase of the study, to begin by 1999, will involve an assessment of cancer incidence and mortality. Although this study is several years away from completion, it should provide a useful means for obtaining information about cancer incidence. Some of the strengths of the study are that it will use existing data systems, identify and assess a large cohort of Gulf War veterans, and can be readily updated over time. One key limitation of the study, however, is that the results cannot be generalized to the entire Gulf War population, since only the New England states will be included. Also, there is likely to be an underreporting of cases in the state registries, particularly cases diagnosed outside of the hospital setting and cases from border areas that may be reported in other state registries outside the New England area.

Conclusions and Recommendation

No direct link has been established between potential exposures that occurred during the Gulf War and the development of tumors among veterans. Yet, concerns have been raised because many of the exposure agents in question have previously been associated with certain cancers. This has led to interest in determining whether the cancer incidence rate among Gulf War veterans is higher than the rates within other appropriate comparison groups. If there is a higher rate that indicates an emerging health problem, then outreach efforts could be conducted to target appropriate diagnosis and treatment to those potentially at risk. The existing data and research applications we reviewed, however, provide very limited information about the incidence of tumors or other illnesses.

To more effectively evaluate the incidence of tumors and other Gulf War illnesses over time, we recommended in our report that the Secretaries of Defense and Veterans Affairs improve existing monitoring capabilities.

Attention should be directed toward strengthening the utility of existing data systems and particularly in developing cost-effective ways to make data systems more compatible with one another so that information from different sources can be linked. In addition, steps should be taken to address the data quality concerns we identified. While we believe such improvements can lead to more effective monitoring capabilities, the existing data systems are likely to be insufficient to answer the question about cancer incidence or other illnesses among Gulf War veterans. Therefore, further research efforts will be needed to supplement the available data systems. For example, little is known about the health status of veterans who receive medical care from sources other than DOD and VA facilities. Practical approaches should be developed to determine whether health problems among these veterans may be emerging.

In response to our report, DOD and VA concurred with our overall findings regarding the inadequacies of existing data systems for assessing the incidence of tumors among Gulf War veterans and our recommendation to improve monitoring capabilities. They emphasized, however, that they have several initiatives underway to strengthen the reporting of health information and the linkage of data from different sources. While we recognize that these efforts will lead to some improvements, we are concerned that the available data sources will continue to be insufficient to assess Gulf War illnesses such as tumors.

GAO's Analysis of Information in VA Databases on Tumors Among Gulf War Veterans

Following completion of our report, we conducted further work, at the Subcommittee's request, to determine the nature and extent of tumors among Gulf War veterans that are included in DOD and VA data systems and demonstrate the feasibility of linking data from different sources. As a first step, we analyzed data from VA's disability benefits and health care reporting systems. Specifically, we requested information on Gulf War veterans who from July 31, 1991 to March 31, 1998, had filed a disability claim based on the presence of one or more malignant or benign tumors or were diagnosed with a tumor at a VA hospital or outpatient medical facility. We obtained cases from five databases maintained by VA: (1) Persian Gulf Health Registry, (2) Patient Treatment File, (3) National Patient Care Database (outpatient), (4) Compensation and Pension Masterfile, and (5) Beneficiary Identification and Records Locator Subsystem.⁸ As shown in table 1 in appendix I, these databases represent different subpopulations of Gulf War veterans, periods of coverage, and levels of

⁸The BIRLS data cover denied and inactive disability claims. The data we obtained from VA, however, do not indicate the reasons claims were denied (e.g., due to lack of service connection, insufficient medical support). As a result, these cases should be viewed as potential tumor cases.

diagnostic information. For example, the Compensation and Pension Masterfile includes up to 6 different diagnoses for an individual, whereas, the Outpatient database records as many as 15 diagnoses.

The data from these reporting systems do not cover Gulf War veterans who remain on active military duty or who have separated from the services and receive non-VA disability benefits or health care. As a result, a significant portion of the Gulf War population will not be included in these data.⁹ In addition, VA omitted a number of codes for tumors, including those for leukemia, Hodgkin's disease, non-Hodgkin's lymphoma, and benign tumors of the gynecological system and mammary glands, from the disability data files they provided us. Consequently, there is some degree of underreporting in the VA data. Nonetheless, these VA data have not been previously combined to show a larger picture of health conditions, such as tumors, among Gulf War veterans.

We completed analyses of the VA data at an aggregate level, the results of which are presented in tables 2-5 (see appendix I). A more detailed analysis, which involves combining cases with similar tumor types, would be more difficult to complete because different diagnostic coding systems are used for the health and disability benefits data.¹⁰ VA has not developed a linkage between these different coding systems.

As shown in table 2, a total of 16,226 cases of tumors were reported for Gulf War veterans across all five databases; the vast majority of the tumors were benign. When we removed duplicate cases by matching social security numbers, the total is reduced to 14,676 veterans with tumors. The fact that a relatively small amount of records (about 10 percent) are duplicated reinforces the need to use multiple data sources to obtain greater coverage of the veteran population. Use of only selective data may lead to an undercount of cases and incomplete information about the health condition of veterans.

Although we do not know whether the total we computed is higher or lower than other appropriate comparison groups, it is a larger number of cases than that reported in other studies of Gulf War veterans. In

⁹According to VA, of the 697,000 servicemembers who participated in the Gulf War conflict, about 568,000 separated from the services, while 128,000 remain on active duty. The majority of veterans separated from the services do not use VA hospitals and medical facilities.

¹⁰The International Classification of Diseases, Version 9 (ICD-9), which is used in VA's Persian Gulf Health Registry, Patient Treatment File, and Outpatient data systems, is ordered by groupings of diseases; VA's disability coding, which is used in the Compensation and Pension and BIRLS data systems, is structured generally by the part of the body affected by the disability or disease.

May 1996, for example, VA provided some information, at the request of the Subcommittee, on the number and types of tumors among Gulf War veterans. In estimating the total number of veterans with tumors, VA used information from three databases: Persian Gulf Health Registry, Patient Treatment File, and Compensation and Pension Masterfile. The total number of tumor cases reported by VA was 6,397 as compared to the 14,676 cases we identified. Our total is much higher because of 2 additional years of data and the inclusion of the BIRLS and outpatient data.

As shown in table 3, a large majority of the Gulf War veterans with tumors also tend to have other diagnosed illnesses as well. This is in line with other published studies of Gulf War illnesses that have noted multiple symptoms and illnesses among the Gulf War veteran population. Further details on the different types of tumors reported from each database are also presented in tables 4-5. Here, it is clear that a broad range of different tumors has been reported for these veterans.

Mr. Chairman, this concludes our prepared remarks. We will be happy to answer any questions you or other members of the Subcommittee may have on our completed and ongoing work.

Table 1: Characteristics of VA Databases Used to Assess Information on Tumors Among Gulf War Veterans

| VA databases | Description | Relevant time period covered | Diagnostic information |
|--|---|------------------------------|--|
| Persian Gulf Health Registry (PGR) | Gulf War veterans completing voluntary medical examinations | Late 1992 to present | Up to 10 diagnoses, coded by ICD-9 ^a |
| Patient Treatment File (PTF) | Veterans receiving inpatient treatment at VA hospitals | Gulf War to present | Up to 10 diagnoses, coded by ICD-9 ^b |
| Outpatient Database | Veterans receiving outpatient treatment at VA medical facilities | 1996 to present | Up to 15 diagnoses, coded by ICD-9 |
| Compensation and Pension (C&P) Masterfile | Veterans with 1 or more service-connected disabilities ^c | Gulf War to present | Up to 6 diagnoses, coded by VA disability categories |
| Beneficiary Identification and Records Locator Subsystem (BIRLS) | Veterans denied and/or no longer receiving disability compensation ^d | Gulf War to present | Up to 9 diagnoses, coded by VA disability categories |

^aInternational Classification of Diseases, Version 9. Up to 1994, only three diagnoses were recorded.

^bIndividuals may have multiple records in the PTF and outpatient files as a result of multiple visits to a VA medical facility. Thus, the number of diagnoses reported for an individual may be larger when multiple records are merged.

^cIncludes veterans whose illnesses are service-connected but who are receiving no compensation as well as veterans receiving pensions. Does not include pending claims.

^dFor veterans whose claims were denied, the database has no information to indicate reasons for denial (e.g., due to lack of service connection, insufficient medical documentation). Diagnostic information reflects what veterans submitted on claim applications. Therefore, these should be viewed as potential cases of veterans with tumors.

Table 2: Number of Gulf War Veterans With Benign and Malignant Tumors, by VA Database

| Database | Benign tumors ^a | Malignant tumors | Total veterans with tumors |
|---|----------------------------|------------------|----------------------------|
| PGR | 837 | 280 | 1,117 |
| PTF | 681 | 606 | 1,287 |
| Outpatient | 2,696 | 1,902 | 4,598 |
| C&P | 4,938 | 709 | 5,647 |
| BIRLS | 3,179 | 398 | 3,577 |
| Total tumors | 12,331 | 3,895 | 16,226 |
| Total number of unique cases^b | 11,550 | 3,126 | 14,676 |

Note: A number of codes for tumors, including those for leukemia, Hodgkin's disease, non-Hodgkin's lymphoma, and benign tumors of the gynecological system and mammary glands, were omitted by VA when it created the C&P and BIRLS databases for our analysis.

^aVeterans with one or more tumors diagnosed as malignant within all possible tumor diagnoses were placed in the "malignant" category. Veterans with only benign tumors were categorized as "benign."

^bGiven that the BIRLS data may reflect potential rather than diagnosed cases of tumors, there is a total number of 11,333 unique cases when the other 4 databases are combined and the BIRLS records are excluded from the analysis (8,502 benign and 2,831 malignant).

Appendix I

Table 3: Number of Gulf War Veterans With Tumors and Other Diagnoses

| Database | Tumor cases | | | | Total veterans with tumors |
|------------|-------------------------------|--------------------------------|-------------------------------------|--------------------------------------|----------------------------|
| | One tumor, no other diagnoses | One tumor plus other diagnoses | Multiple tumors, no other diagnoses | Multiple tumors plus other diagnoses | |
| PGR | 260 | 830 | 10 | 13 | 1,113 |
| PTF | 233 | 775 | 20 | 259 | 1,287 |
| Outpatient | 1,671 | 2,016 | 212 | 697 | 4,596 |
| C&P | 136 | 5,276 | 7 | 196 | 5,615 |
| BIRLS | 464 | 2,982 | 20 | 110 | 3,576 |

Note: Table does not reflect 39 missing cases of unspecified tumors. As a result, the numbers in the column for total veterans with tumors will differ somewhat from the numbers in the same column in table 2.

Table 4: Number of Tumors in Gulf War Veterans, by VA Health Administration Databases

| Diagnostic code | Type of tumor | PTF | Outpatient | PGR |
|------------------|--|-------|------------|-----|
| Malignant | | | | |
| 140 - 149 | Lip, oral cavity and pharynx | 91 | 206 | 8 |
| 150 - 159 | Digestive organs and peritoneum | 341 | 814 | 17 |
| 160 - 165 | Respiratory and intrathoracic organs | 357 | 821 | 13 |
| 170 - 176 | Bone, connective tissue, skin and breast | 323 | 1,531 | 112 |
| 179 - 189 | Genitourinary organs | 389 | 1,159 | 45 |
| 190 - 199 | Other unspecified sites | 2,645 | 1,170 | 36 |
| 200 - 208 | Lymphatic and hematopoietic tissue | 702 | 1,848 | 58 |
| Benign | | | | |
| 210 | Lip, oral cavity and pharynx | 23 | 122 | 11 |
| 211 | Other parts of digestive system | 137 | 753 | 56 |
| 212 | Respiratory and intrathoracic organs | 31 | 60 | 5 |
| 213 | Bones and articular cartilage | 32 | 42 | 22 |
| 214 | Lipoma | 176 | 901 | 296 |
| 215 | Other connective and other soft tissues | 31 | 128 | 26 |
| 216 | Skin | 68 | 1,439 | 206 |
| 217 | Breast | 16 | 57 | 3 |
| 218 | Uterine leiomyoma | 136 | 342 | 30 |
| 219 | Other, uterus | 10 | 15 | |
| 220 | Ovary | 8 | 5 | 1 |
| 221 | Other female genital organs | 3 | 15 | |
| 222 | Male genital organs | 2 | 69 | 9 |
| 223 | Kidney or other urinary organs | 3 | 20 | 3 |

(continued)

Appendix I

| Diagnostic code | Type of tumor | PTF | Outpatient | PGR |
|------------------------|---|--------------|-------------------|--------------|
| 224 | Eye | 2 | 63 | 1 |
| 225 | Brain and other parts of nervous system | 30 | 94 | 6 |
| 226 | Thyroid gland | 15 | 23 | 2 |
| 227 | Other endocrine glands and related structures | 40 | 87 | 4 |
| 228 | Hemangioma and lymphangioma, any site | 43 | 80 | 38 |
| 229 | Other and unspecified sites | 9 | 107 | 13 |
| | Carcinoma in situ | | | |
| 230 | Digestive organs | 5 | 28 | |
| 231 | Respiratory system | 2 | 24 | 1 |
| 232 | Skin | 1 | 40 | 3 |
| 233 | Breast and genitourinary system | 19 | 91 | 4 |
| 234 | Other and unspecified sites | 1 | 28 | 1 |
| | Neoplasms of uncertain behavior | | | |
| 235 | Digestive and respiratory organs | 33 | 35 | 2 |
| 236 | Genitourinary | 13 | 57 | 10 |
| 237 | Endocrine glands and nervous system | 33 | 76 | 21 |
| 238 | Other and unspecified sites and tissues | 63 | 432 | 32 |
| 239 | Unspecified nature | 46 | 387 | 46 |
| Total | | 5,879 | 13,199 | 1,141 |
| | Number of other non-tumorous diseases | 444 | 459 | 269 |
| | Number of other non-tumorous diagnoses | 8,621 | 8,677 | 1,745 |

Appendix I

Table 5: Frequency of Tumors in Gulf War Veterans, by VA's Benefits Administration Databases

| Diagnostic code | Type of tumor | BIRLS | C&P |
|------------------------|--|--------------|----------------|
| 5012 | Bones, new growth, malignant | 30 | 34 |
| 5015 | Bones, new growth, benign | 229 | 657 |
| 5327 | Muscle, new growth, malignant - excludes soft tissue sarcoma | 4 | 4 |
| 5328 | Muscle, new growth, benign | 26 | 45 |
| 5329 | Soft tissue sarcoma | 1 | 12 |
| 6014 | Eyeball, new growth, malignant | 2 | 3 |
| 6015 | Eyeball, new growth, benign | 43 | 82 |
| 6208 | Ear, new growth, malignant | 1 | |
| 6209 | Ear, new growth, benign | 12 | 46 |
| 6819 | Respiratory system, new growth, malignant | 57 | 85 |
| 6820 | Respiratory system, new growth, benign | 145 | 237 |
| 7343 | Digestive system, any specified part, new growth, malignant | 67 | 57 |
| 7344 | Digestive system, any specified part, new growth, benign | 80 | 187 |
| 7528 | Genitourinary system, new growth, malignant | 51 | 148 |
| 7529 | Genitourinary system, new growth, benign | 194 | 297 |
| 7627 | Gynecological system, new growth, malignant | 34 | 65 |
| 7628 | Gynecological system, new growth, benign | 9 | 18 |
| 7818 | Skin, new growth, malignant | 156 | 248 |
| 7819 | Skin, new growth, benign | 2,740 | 3,742 |
| 7914 | Endocrine system, new growth, malignant | 11 | 52 |
| 7915 | Endocrine system, new growth, benign | 20 | 60 |
| 8002 | Brain, new growth, malignant | 36 | 53 |
| 8003 | Brain, new growth, benign | 20 | 75 |
| 8021 | Spinal cord, new growth malignant | 7 | 9 |
| 8022 | Spinal cord, new growth, benign | 3 | 20 |
| Total | | 3,978 | 6,236 |
| | Number of other non-tumorous diseases | 448 | 530 |
| | Number of other non-tumorous diagnoses | 12,620 | 22,576 |