

NAACCR Town Meeting
VA Hospitals Reporting: Issues and Resolution Efforts
September 21, 2006
3:00 pm Eastern; 2:00 pm Central; 1:00 pm Mountain; 12:00 pm Pacific

Present – Representatives from the following registries and organizations:

54 U.S.: Alaska Cancer Registry, American Cancer Society, Arizona Cancer Registry, California Cancer Registry, California Cancer Surveillance Program, Region 3, Cancer Registry of Northern California, Desert Sierra Cancer Surveillance Program, Los Angeles Cancer Surveillance Program, Northern California Cancer Center, Tri-counties Cancer Surveillance Program, Centers for Disease Control and Prevention, Central Brain Tumor Registry of the US, Colorado Central Cancer Registry, Department of Defense, Florida Cancer Data System, Georgia Comprehensive Cancer Registry, Metropolitan Atlanta and Rural Georgia SEER Registry, Cancer Data Registry of Idaho, Illinois State Cancer Registry, Indiana State Cancer Registry, State Health Registry of Iowa, Kansas Cancer Registry, Kentucky Cancer Registry, Louisiana Tumor Registry, Maine Cancer Registry, Maryland Cancer Registry, Massachusetts Cancer Registry, Michigan Cancer Surveillance Program, Metropolitan Detroit Cancer Surveillance System, Minnesota Cancer Surveillance System, Missouri Cancer Registry, Montana Central Tumor Registry, National Cancer Institute, Nebraska Cancer Registry, Nevada Statewide Cancer Registry, New Hampshire State Cancer Registry, New Jersey State Cancer Registry, New York State Cancer Registry, North Carolina Central Cancer Registry, North Dakota Cancer Registry, Ohio Cancer Incidence Surveillance System, Oklahoma State Department of Health, ORC Macro International, Inc., Pennsylvania Cancer Registry, Puerto Rico Central Cancer Registry, South Dakota Cancer Registry, Tennessee Cancer Registry, Texas Cancer Registry, Vermont Cancer Registry, Virginia Cancer Registry, Washington State Cancer Registry, Westat, Inc., Wisconsin Cancer Reporting System

5 NAACCR Staff: Dr. Holly Howe, Moderator – Executive Director, Joellyn Ellison – Program Manager of Data Evaluation and Publication, Royale Anne Hinds – Assistant to the Executive Director, and Lori Havener – Program Manager of Standards, Shannon Vann – Program Manager of Education and Training

1. Introduction and Background

Holly Howe

For many years, groups within NAACCR have been addressing reporting issues on different levels with VA Hospitals. The NAACCR Board wants members to be aware of the various approaches that standard setters and leadership organizations have taken to address the issues on reporting from the VA Hospitals. There is an addition to the agenda. Reda Wilson will speak about NPCR's work on similar reporting issues. There will be an opportunity for registries to discuss their experiences and look for strategies for resolution.

2. NCCCS History and Attempts to Resolve Issue

Dee West

Dee West is the chairperson of the National Coordinating Council for Cancer Surveillance, of which NAACCR and standard setters are members. Dee West explained

that state laws have no jurisdiction over the federal hospitals and medical facilities. We try to bring them in on a voluntary basis to fulfill our mission. In general, we have been successful to resolve most issues. However, the latest issue is that state cancer registries are not getting access to the data at all or if they do get access to the data, the people cannot be re-contacted for follow-up, follow-back, Quality Control, or even for research studies. If patients can not be contacted, you can get incidence counts, but they can not be included in further research because that would be re-disclosure. In California, some VA Hospitals are willing to send data, but not to re-disclose. At the August NCCCS meeting, this issue was discussed when changes in HIPAA affected VA reporting. The NCCCS invited VA representative Raye Anne Dorn and her supervisor to discuss the problems and interpretation and application of the new rules on cancer reporting. The NCCCS is monitoring the situation and would like the VA to meet with them to discuss the issue, but that meeting has not been organized.

3. 2005 Reporting Issues in California

Bill Wright

Bill Wright explained that the problem in California is the re-release of personal identifying information that the VA has released to them. He spent a considerable amount of time last year researching the VAs published policies and the Federal Code. A letter received from the VA in San Diego stated that the data could not be released subject to criminal sanctions of Federal Code 38USC5701F. Code 5701F does not speak about re-release of data. It states that the VA may give data to civil law enforcement agencies that are charged under applicable law for protection of public health and safety for a purpose authorized by law. If you willfully use the data for other purposes, you can go to jail. Since passed in 1985, California law specifically says that the data must be used for research into causes and cures of cancer. California Cancer Registry has sent a standing letter every three years asking the VA registry to voluntarily participate. In the letter, they included what the data would be used for. The California Cancer Registry is not a covered HIPAA entity.

In March 2006, Bill sent a letter to all the VA facilities in California. He reviewed the letter which covered all aspects of the VA facilities' policies, codes, and concerns in the letter. He has received one response from San Diego, which stated that they could not release the information per Code 5701F. Bill has been told there are Federal Regulations that will not allow them to release the data, but no one has given him the specific restrictions. If California is prohibited from having the data, Bill needs the restrictions in writing to give to his state department. Bill has not been able to find out who is in charge of the policies governing VA registries or VA reporting for public purposes.

Holly asked for clarification on reporting on incidence data. Bill said California, with the exception of San Francisco, is not receiving incidence reports from the VA registries. This total is approximately over 4,000 cases per year. These counts would predominately be men and it would affect prostate cancer counts and other male-related cancers to the greatest extent.

4. 2006 Research Access to VA Cases

Dennis Deapen

Dennis Deapen, former President of NAACCR, reported the following:

“For those of us that have been involved in central cancer registries for many years, we have seen the rapid elevation of population-based cancer research and involvement of cancer registries in the last few years.

While I don't think anyone compiles exact numbers of these nationwide, I would guess that in 2006 there might be between 100-300 funded research studies using registry data, at the cost of hundreds of millions of dollars, much of which comes from the National Cancer Institute.

With the loss of VA data, none of these studies can any longer be characterized as population-based. Furthermore, we know that the distribution of types of cancer, race, age and gender of VA patients differ from the general population. The omission of these patients has introduced uncorrectable bias in the results of these studies. Of course, the impact of this omission is particularly ironic for researchers within the VA. As they request registry data – either for general population-based research, or more likely to study VA patients – we must inform them that this is no longer possible.

Again, looking back at the national advances in cancer surveillance, the public demanded, and congress supported, the ability to monitor cancer incidence and mortality nation-wide. It is only very recently, that this has become a reality through the collaboration of the National Cancer Institute, the Centers for Disease Control and Prevention, NAACCR, and the extreme dedication and hard work of central and hospital cancer registrars across the nation. Just two weeks ago, the Annual Report to the Nation presented the most comprehensive data on the national cancer burden. Yet, if the current VA crisis is not corrected, it will also be the last.

So what does this mean for the long term? Even if all of the missing VA data were available for research today, many of the current studies will not be able to recover. Population-based cancer research from the mid 2000s will forever require an asterisk, reminding us that it wasn't truly population-based. And it remains to be seen what the impact on future research funding may be.

The picture is a little brighter for the national cancer statistics. If all of the missing VA data were made available today, we may well be able to include them in next year's US cancer statistics. If there is further delay, next years' Report to the Nation will also require an asterisk, or perhaps a sticker on the cover, to remind researchers and the public that they are not correct.

To summarize, I believe that “crises” is not too strong a term to use to describe the current situation and it is imperative that the proper resolution be achieved promptly.

I'll close on a personal note: both of my parents were veterans – both as volunteers. As everyone on this call knows, our nation has not always treated our veterans with respect. My mother died of cancer. Yet, if she was diagnosed today, she would not be allowed the same rights to participate in research as the rest of the population. My father is an epidemiologist. If he develops cancer, he also will be deprived of this right, despite his devotion to public health work. Beyond the data, and research protocols, VA patients are real people, and they deserve greater respect.”

Reda Wilson, the program consultant at NPCR, has been researching the VA reporting issues for NPCR for one year and reported the following:

They have learned that over the years, the VA health facilities have consistently reported all deaths to their local/state health departments, including deaths occurring in non-residents of the state in which the facility is located. Also, VA has placed no restrictions on the use of the mortality data being re-released for research purposes.

VA facilities voluntarily report to the states' HIV/AIDS registries, again including non-residents of the state in which the facility is located and placing no restrictions on the use of this data for research. Agreements were reached with the VA Health Administration to facilitate the reporting of HIV/AIDS data through legal opinions within CDC and VA.

A Memorandum of Understanding at the Secretary (Cabinet) level has been established with VA Health Administration and HHS to work with CDC to collecting, analyzing, and reporting on data regarding obesity and diabetes.

These examples give NPCR something to build upon to reach a collaboration agreement with local, state, and national registries. Last year, NPCR collected data using the NPCR Annual Program Evaluation Instrument (APEI) from their registries regarding issues with VA facilities. The following information is what was found:

- Inconsistent, Delayed, Incomplete, or No Reporting 24 states
- Reporting from VACCR 1 state
- No Issues at the Time of Evaluation 22 states
- No Information on Penalties 5 states
- Penalty in Cancer Registry Law 20 states
- Penalty in General Public Health Law 10 states
- Penalty Associated with Reimbursement or Licensure 5 states
- No Penalties 8 states

Information from the 2006 APEI regarding reporting from VA facilities:

- Data Abstracted by Central Cancer Registry Staff 5 states
- Data Abstracted by Combination CCR and VA Staff 13 states
- Data Reported by VACCR for ≥ 1 VA Facility 9 states
- Estimated Number of Cases Missed Nationwide 10,201

This information has been forwarded through to the highest levels of CDC, and currently is at the Center level, the same status which was reported to the NCCCS in January 2006. The request is for an agreement between the VA Health Administration and HHS for cancer, similar to the ones on obesity, diabetes, and HIV/AIDS.

6. Experiences of Other Registries

Open Forum

South Dakota is getting all data because they completed a process with the assistance of the VA's privacy lawyer in Washington, DC.

Bill Wright commented that if you tell them under state law that you will be re-releasing the data for research, they will not agree to participate.

Kentucky has reporting by two VA facilities. The most cooperative VA facility has sent them a very restrictive data exchange agreement which prohibits the use of the data. They can only use the data for incidence statistics and release to National Programs.

Iowa received a dataset which did not include non-residents. They are no longer allowed to check completeness for VA facility cases. Over the last six months, Iowa has cooperated with two national research groups out of the VA.

Missouri has letters of agreement in place, but they are having trouble getting the cases to Missouri, death clearance & follow-back, getting information on cases that have been reported out-of state, on death certificates, or with states which they have case sharing agreements.

Wisconsin has two VA registries, from which they have received complete reporting for only one year of the last ten years.

Virginia asked how many registries have been contacted about a Persian Gulf War Veteran study. Ohio and Massachusetts were contacted. Massachusetts told them that they could not give them the data and then contacted Raye Anne Dorn. Raye Anne said they could release the VA information to the study.

Minnesota has had good reporting for many years, but recently the neighboring states are not reporting the out-of-state cases. Minnesota has been denied access at the VA facilities for follow-up information. They have been told they may not be able to do case finding on non-Minnesota residents.

New Jersey is no longer allowed to audit their one VA facility. Numbers are not coming from New York and Philadelphia. They are observing substantially lower case counts of prostate cancer cases and believe the VA situation is contributing to the undercount.

South Dakota reported that the VA has set up a regional registry for South Dakota, Nebraska, and Iowa. They are not experiencing problems.

Nebraska, also receiving from the regional registry, gets a download every six months of Nebraska residents. Nebraska's standing letter with the VA does not mention what they are going to do with the cases.

Virginia has no reporting issues with the VA. They do have a current agreement letter with them.

Texas has been getting data from seven facilities, but is not sure about the non-Texas residents.

New Mexico has no reporting issues with the VA.

Detroit has no reporting issues with the VA.

Arizona has two out of three VA facilities reporting. VA facilities have been cooperative when sent death certificates.

Pennsylvania has been receiving data, but they do not receive out-of-state data. They recently stopped reporting non-analytic cases (i.e. those diagnosed in and receiving all

first-course therapy in another facility), but they are still reporting analytic cases. They are prohibited from re-releasing on a case level basis. They are involved in the Gulf War Study.

North Carolina has regular reporting from VA facilities.

New Hampshire asked if the states that are not having trouble with reporting are also allowed to do case finding. Texas reported they have not done case finding, but they are allowed to do death clearance follow-back. Nebraska and South Dakota reported they are allowed to do case finding.

7. Strategy: Working with the ACS

Liz Ward

American Cancer Society (ACS) tracks mortality and incidence rates closely as measures of progress. Liz asked if there are groups outside of the federal government or federally funded registries that could play a role in resolving this issue?

Vivien Chen from Louisiana suggested contacting a veteran's group.

Christie Schmidt, Senior Director of Public Policy from ACS, feels that getting outside help to resolve this is a good idea. Christie asked if the problem seem to be the VA's interpretation of HIPAA or is their internal interpretation is different in different areas of the country.

Bill Wright responded that no one seems to want to take responsibility for the interpretation or getting an interpretation is trapped below the person that needs to clarify. Bill suggested contacting Senator Feinstein to ask why the VA is refusing to collaborate with its federally charged sister agencies in the fight against cancer.

Dennis reported that HIPAA was a barrier three to four years ago, but currently it should not be an issue. Cancer is not on a lower importance level than other diseases, such as diabetes or HIV/AIDS.

Holly and Christie will discuss the possibility of getting a small group together to identify the issue and what the implications are of the missing data. After a strategy has been created, Christie can work with a Congressional Lobbyist in Washington DC to find the best way to approach the government.

8. Closing Remarks

Holly Howe

If anyone would like to be part of the group working with the cancer surveillance department of ACS, contact Holly Howe. This will become a major activity for the organization.

There will be another NAACCR Town Meeting on October 10, 2006 on the committee activities of the Data Use and Research Committee and the Data Evaluation and Certification Committee