REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

CANCER REGISTRY STUDY PURSUANT TO HJR 524 AND SB 942

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

HOUSE DOCUMENT NO. 73

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Preface

House Joint Resolution (HJR) 524, agreed to by the 1999 General Assembly, directed the Joint Commission on Health Care (JCHC) to study Virginia's statewide cancer registry (Appendix A). Specifically, HJR 524 directed JCHC to examine the effectiveness of the Virginia cancer registry in terms of:

- completeness of the registry data;
- timeliness of data reporting, collation and analysis;
- manner and thoroughness of data collation, including any geographic and population subcomponents;
- uses of the cancer registry data for prevention, treatment, and intervention analyses and strategies;
- access to the registry data by experts for research purposes and by the public for educational purposes;
- confidentiality of the registry data;
- legal basis for the Virginia cancer registry; and
- principles and practices currently in use for cancer control in Virginia.

Senate Bill (SB) 942, enacted by the 1999 General Assembly, directs JCHC to analyze the exchange of patient-identifying information pursuant to reciprocal data-sharing agreements with other state cancer registries, and confidentiality protections for patient data. SB 942 also directs JCHC to examine the potential for inappropriate disclosure of patient data as a result of such data exchange, and whether the patient should be required to consent to disclosure or authorized to bar such disclosure (Appendix B).

Based on our research and analysis during this review, we concluded the following:

- a cancer registry is an important tool for cancer control and prevention, since cancer registry data can be used to identify trends and evaluate the effectiveness of prevention methods;

- all hospitals, clinics, independent pathology laboratories, and physicians in Virginia are required by law to report information on patients diagnosed with cancer to the Virginia Cancer Registry (VCR);

- cancer registries, in order to be effective, must contain data on as large a percentage of actual cancer cases as possible but VCR's completeness rate has historically been relatively low particularly in terms of cases reported by small hospitals that do not have their own internal cancer registries;

- the VCR has not yet achieved certification from the North American Association of Central Cancer Registries (NAACCR) primarily because the percentage of all cancer cases that actually appear in the VCR (estimates have ranged from 77 to 87 percent) is relatively low compared to the 95 percent required by NAACCR standards;

- unlike Virginia, several other states have field staff who work on site with medical providers to ensure complete, accurate reporting of all cancer cases - the U.S. Centers for Disease Control has previously recommended that the VCR hire an additional staff person to collect cancer case data in small hospitals;

- VCR data are confidential however individual-level data may be released for research purposes if the research will benefit the public health of Virginians, and if the recipient can and will protect individual anonymity;

- overall, the confidentiality of VCR data appears to be adequately protected;

- mandatory reporting of patient-identifying information is essential for effective cancer surveillance, but improved patient notification of VCR reporting requirements could help mitigate any public misperceptions concerning VCR;

- Oregon is the only state that has a mandatory cancer registry notification program for cancer patients.

A number of policy options were offered for consideration by the Joint Commission on Health Care regarding the issues discussed in this report. These policy options are listed on pages 35-36.

Our review process on this topic included an initial staff briefing, which comprises the body of this report. This was followed by a public comment period during which time interested parties forwarded written comments to us regarding the report. The public comments (attached at Appendix B) provide additional insight into the various issues covered in this report.

On behalf of the Joint Commission on Health Care and its staff, I would like to thank the Virginia Department of Health, and in particular the management and staff of the Virginia Cancer Registry, for their cooperation and assistance during this study.

Patrick W. Finnerty
Executive Director

December, 1999

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Authority for the Study

House Joint Resolution (HJR) 524, agreed to by the 1999 General Assembly, directed the Joint Commission on Health Care (JCHC) to study Virginia's statewide cancer registry (Appendix A). Specifically, HJR 524 directed JCHC to examine the effectiveness of the Virginia cancer registry in terms of:

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This report is organized into five sections. This section briefly discusses the authority for the study and its organization. The second section discusses the need for cancer surveillance activities. The third section examines various aspects of the operations of the Virginia Cancer

Registry. The fourth section discusses how the Virginia Cancer Registry data can be used to support the state's overall cancer prevention and control efforts, while at the same time protecting the confidentiality of the information. The final section contains policy options developed by JCHC staff.

II.

The Need for Cancer Surveillance Activities

Cancer is a Leading Cause of Death in Virginia

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. Cancer is the second leading cause of death in the United States, exceeded only by heart disease. The American Cancer Society (ACS) estimates that approximately 563,000 Americans will die from cancer during 1999, representing approximately 25 percent of all deaths expected to occur in the United States.

In Virginia, cancer is responsible for approximately 24 percent of all deaths. From 1994 through 1997, cancer accounted for more than 12,000 deaths annually in Virginia (Figure 1). An estimated 13,300 cancer-related deaths will occur in Virginia during 1999, with 28 percent of the cancer-related deaths expected to be as a result of lung cancer.

Four Types of Cancer Are Particularly Prevalent

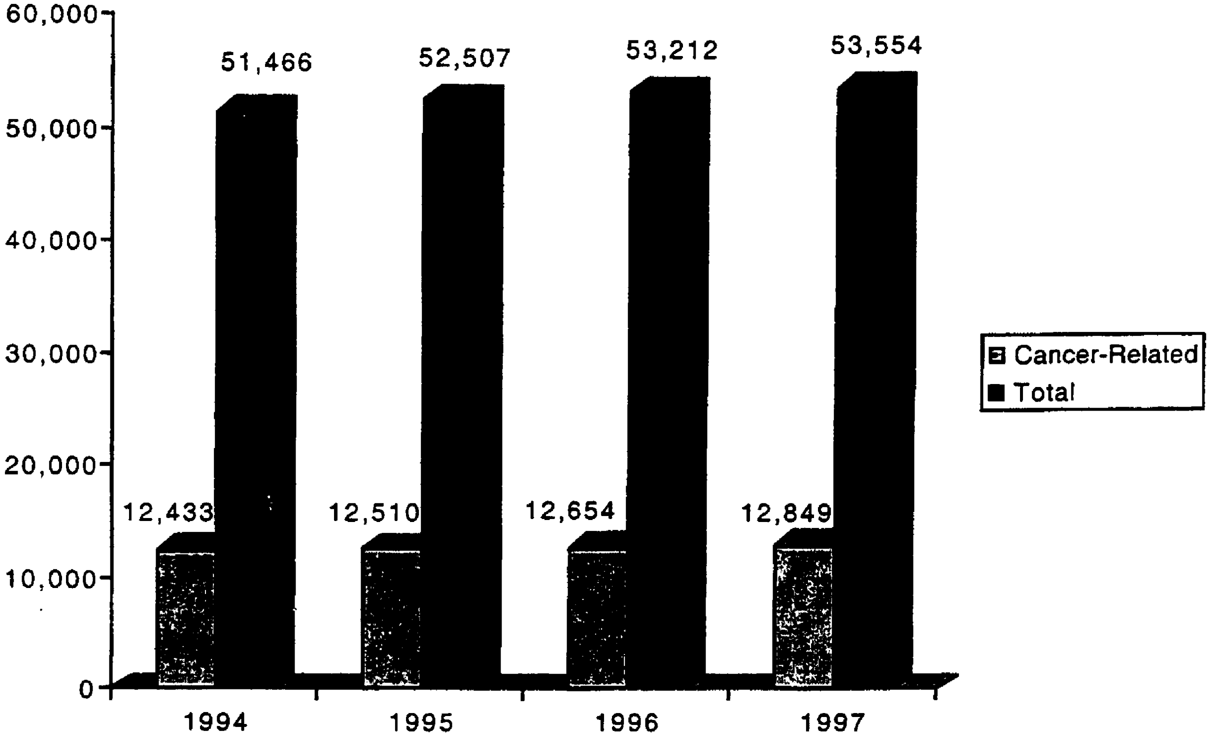
More than 12 million new cancer cases have been diagnosed nationally since 1990. The most prevalent forms of cancer in Virginia, as is the case nationally, are breast, lung and bronchus, prostate, and colon and rectum. These four anatomical sites account for approximately 56 percent of all cancer cases in Virginia (Figure 2).

An estimated 1.2 million new cancer cases are expected to be diagnosed in the United States during 1999. It is estimated that 29,000 new cancer cases will be diagnosed in Virginia during 1999. According to this estimate, four sites will be responsible for 54 percent of the new cases:

- prostate – 4,300 cases,
- breast – 4,200 cases,
- lung/bronchus – 4,100 cases, and
- colon/rectum – 3,000 cases.

Figure 1

Cancer-Related Deaths in Virginia Compared to Total Deaths



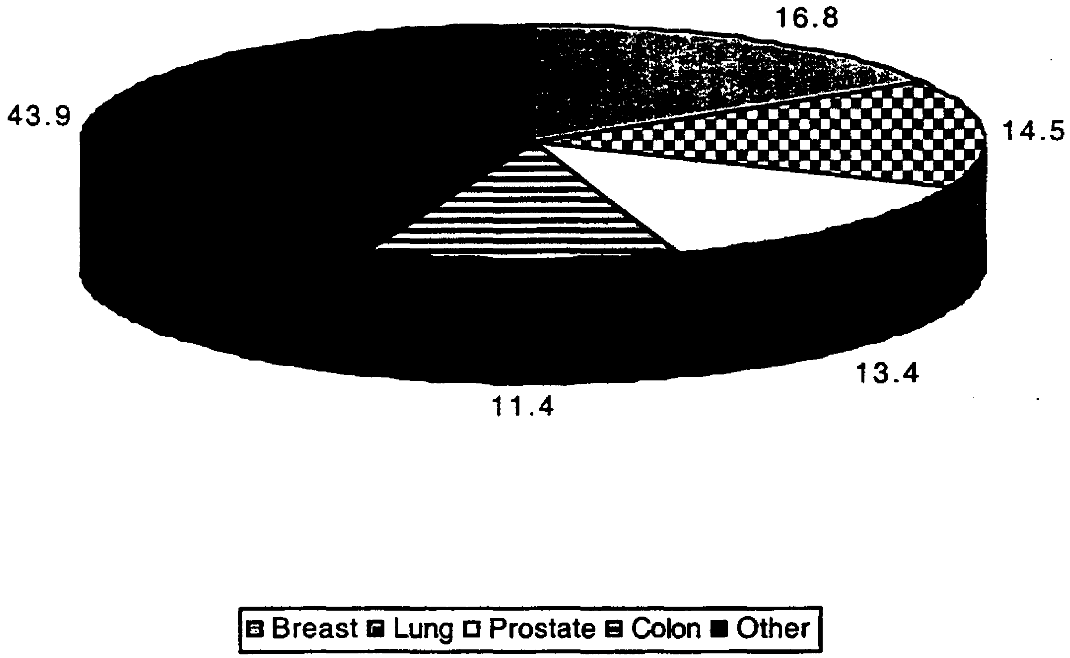
Source: Virginia Cancer Registry data for 1994-1997.

Anyone is at Potential Risk of Developing Cancer, But It Tends to Be More Prevalent in Older Individuals

Anyone is at least some potential risk of developing cancer during his or her lifetime. Cancer can be caused by external factors, such as chemicals, radiation, and viruses. Internal factors, such as hormones, immune conditions, and inherited mutations, can also cause cancer. According to the ACS, causal factors may act together or in sequence to initiate or promote the disease, with ten years or more often passing between exposures to causal factors and initial cancer detection.

Figure 2

Percentage Distribution of Reported Cancers in Virginia, By Primary Site



Source: Virginia Cancer Registry data for 1994-1997.

However, the occurrence of cancer increases as individuals age. Most cancer cases in Virginia, as in the United States as a whole, are found in individuals who are middle-aged or older. In Virginia:

- 90 percent of cancer cases occur in individuals 40 years of age or older,
- 64 percent of cancer cases occur in individuals 60 years of age or older, and
- 37 percent of all cancer cases occur in individuals 70 years of age or older.

A Cancer Registry is a Disease Surveillance Tool Intended to Collect Accurate, Timely Cancer-Related Data

Cancer surveillance is a term used to describe the ongoing, systematic collection and analysis of information on new cancer cases and cancer deaths. Cancer data can be used to identify trends over time, discover cancer patterns among various populations, and to evaluate the effectiveness of screening or other prevention measures. Ideally, data collected through surveillance should be analyzed with the intent of making health care policy decisions potentially affecting disease treatment and/or resource allocation.

One of the primary cancer surveillance tools is a cancer registry. A cancer registry is a data system designed for the collection, management, and analysis of data on persons with the diagnosis of cancer. Cancer registries can be classified into three general types:

- hospital based registries collect information about all cancer patients diagnosed and or treated at a particular institution;
- central registries are typically population-based and collect data on all cancer patients who are residents of a particular area such as a state; and
- special purpose registries collect data on only one type or aspect of cancer.

Central cancer registries are typically operated by public health agencies. There is no one cancer surveillance system that collects data on all cases diagnosed in the United States each year. Rather, collection of cancer data in the U.S. has developed under several systems of registries. There are currently three major cancer surveillance programs in the United States: the National Cancer Database (NCDB), the Surveillance, Epidemiology, and End Results Program (SEER), and the National Program of Cancer Registries.

The NCDB is a program of hospital registries of the American College of Surgeons' Commission on Cancer. All hospitals with cancer treatment programs approved by the American College of Surgeons are required to have a cancer registry. The NCDB is jointly administered by the ACS for the purpose of ensuring quality cancer care by providing data for evaluation of patient management within hospitals and other treatment centers, and for comparisons between institutions and regions of the country. Approximately 1,500 cancer treatment centers in the U.S. contribute data to the NCDB.

The National Cancer Institute's SEER program is a population-based registry which collects data on a selected sample of the population in five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and six metropolitan areas (Atlanta, Detroit, Los Angeles, San Franciso/Oakland, San Jose/Monterey, and Seattle). Overall, the SEER program covers about 14 percent of the U.S. population. Cancer cases are followed-up annually to determine survival. These data, along with data on cancer-related deaths from the National Center for Health Statistics, are analyzed to provide incidence, mortality, and survival rates.

The United States Centers for Disease Control and Prevention Has Established A National Program of Cancer Registries

The National Program of Cancer Registries (NPCR) was authorized by the federal Cancer Registries Amendments Act of 1992. This legislation was enacted in response to a perceived need to collect data on larger percentages of state populations. This legislation authorized the Centers for Disease Control and Prevention (CDC) to provide funds to states and territories to:

- improve existing cancer registries;
- plan and implement registries where they do not exist,
- meet standards for completeness, timeliness, and quality,
- train registry personnel, and
- establish a computerized reporting and data processing system.

According to the CDC, cancer surveillance serves as the foundation for a national comprehensive strategy to reduce illness and death from cancer. As envisioned by the CDC, cancer surveillance conducted by state-based registries is designed to:

- determine cancer patterns among various populations;

- monitor cancer trends over time,

- guide planning and evaluation of cancer control programs;
- help prioritize health resource allocations,

- advance clinical, epidemiological, and health services research, and

- serve as the basis for an aggregated and centralized database of cancer incidence in the United States.

NPCR currently provides $24 million in support to 49 state cancer registry programs. Funding is used in 36 states for enhancement of established central registries and for planning and implementation of registries in 13 states. Ultimately, CDC would like to provide even greater financial support for more aggressive utilization of registry data to serve as the basis for public health interventions. The ultimate goal of the NPCR is for all states to establish registries and move beyond the enhancement level to comprehensive, quality registries that meet critical cancer information needs.

When fully operational, NPCR will collect incidence data on 97 percent of the U.S. population. CDC envisions that this level of population coverage can serve as the basis for development of a national, centralized cancer database. In strengthening the national network of cancer registries, the NPCR works closely with other federal agencies and with national organizations such as the American Cancer Society, the American College of Surgeons, the National Cancer Registrars Association, the National Cancer Institute, and the North American Association of Central Cancer Registries.

III.
Operations of the Virginia Cancer Registry

The Virginia Cancer Registry is Authorized, Operated and Maintained Pursuant to the *Code of Virginia*

The Virginia Cancer Registry (VCR) began in 1970, with hospitals reporting cancer cases on a voluntary basis to the central registry for data warehousing purposes. In 1990, the *Code of Virginia* was amended to require that all Virginia hospitals, clinics and independent pathology laboratories report cancer cases to the VCR. In 1998, the *Code of Virginia* was further amended to require individual physicians to "report information on patients having cancers unless he has determined that a hospital, clinic, or in-state pathology laboratory has reported the information."

According to section 32.1-70 of the *Code of Virginia*, information to be reported concerning individuals having cancer shall include:

- name,
- address,
- sex,
- race,
- diagnosis,
- any other pertinent identifying information, and
- information regarding possible exposure to Agent Orange or other defoliants through their development, testing or use or through service in the Vietnam War.

The purpose of the VCR, as defined by Section 32.1-70 of the *Code of Virginia*, includes but is not limited to:

- determining means of improving the diagnosis and treatment of cancer patients;

- determining the need for and means of providing better long-term, follow-up care of cancer patients;
- conducting epidemiological analyses of the incidence, prevalence, survival, and risk factors associated with the occurrence of cancer in Virginia;
- collecting data to evaluate the possible carcinogenic effects of environmental hazards including exposure to dioxin and the defoliant Agent Orange;
- improving rehabilitative programs for cancer patients;
- assisting in the training of hospital personnel; and
- determining other needs of cancer patients and health personnel.

Data Reporting Requirements Have Been Implemented Through Administrative Regulations

Through administrative regulations, found at 12 VAC 5-90-180, the Virginia Department of Health has defined specific types of data that must be reported to the VCR (Figure 3). Health department regulations state that reporting to the VCR shall be done via electronic means where possible, in conformance with standards developed by the North American Association of Central Cancer Registries (NAACCR). A copy of patient admission forms, pathology reports, and discharge summaries are also required to be submitted to the VCR. State regulations further specify that reports shall be made to VCR within six months of the diagnosis of cancer, and shall be submitted on a monthly basis.

The Virginia Cancer Registry Operates Within a Broader Disease Surveillance System Administered by the Department of Health

Section 32.1-39 of the *Code of Virginia* requires the State Board of Health to provide for "the surveillance of and investigation into all preventable diseases and epidemics in the Commonwealth." In order to carry out this responsibility, the State Health Commissioner has broad statutory authority to examine medical records. Section 32.1-40 of the *Code of Virginia* states that:

Figure 3

Information Required to Be Reported to the Virginia Cancer Registry

- Patient's Name
- Age
- Sex
- Date of admission or first contact
- Histology
- Social Security Number
- Ethnicity
- Usual occupation
- Sequence number
- Laterality
- Name of reporting facility
- Cause of death (if applicable)
- History of tobacco and alcohol use
- Address
- Date of birth
- Date of diagnosis
- Primary site of cancer
- Basis of diagnosis
- Race
- Marital status
- Usual industry
- Stage of diagnosis
- Recurrence information (if applicable)
- Vital status
- Date of last contact
- History of service in Vietnam War and exposure to dioxin-containing compounds

Source: Virginia Department of Health – Regulations for Disease Reporting and Control (January 1999).

every practitioner of the healing arts and every person in charge of any medical care facility shall permit the Commissioner or his designee to examine and review any medical records which he has in his possession or to which he has access upon request of the Commissioner or his designee

> in the course of investigation, research, or studies of diseases or deaths of public health importance.

Routine disease reporting in a timely manner is very important to disease intervention. In addition to cancer, there are 65 reportable diseases pursuant to state regulations.

Cancer Case Reports in Virginia Have Been Increasing, With Most Reports Coming from Hospitals That Have Their Own Cancer Registries

Cancer registration begins with "case finding," or the identification of people with cancer who have sought care at hospitals or other medical care settings. Most often, the patient's physician initiates the data record by noting the cancer site and type, patient demographics, and extent of disease or "stage" in the medical record. Such data are then reported to a central cancer registry. In Virginia, 130,966 cancer cases were reported to the VCR from 1992 through 1996 (Figure 4). The number of new cancer cases reported annually to VCR increased by nine percent from 1992 through 1996.

VCR staff estimate that 86 percent of the cases currently reported to it come from hospitals that operate their own cancer registries. Non-hospital facilities, by comparison, account for only 2 percent of the cancer cases reported to the VCR (Figure 5). Among the 98 hospitals currently reporting to VCR, 63 have their own cancer registries and 35 do not.

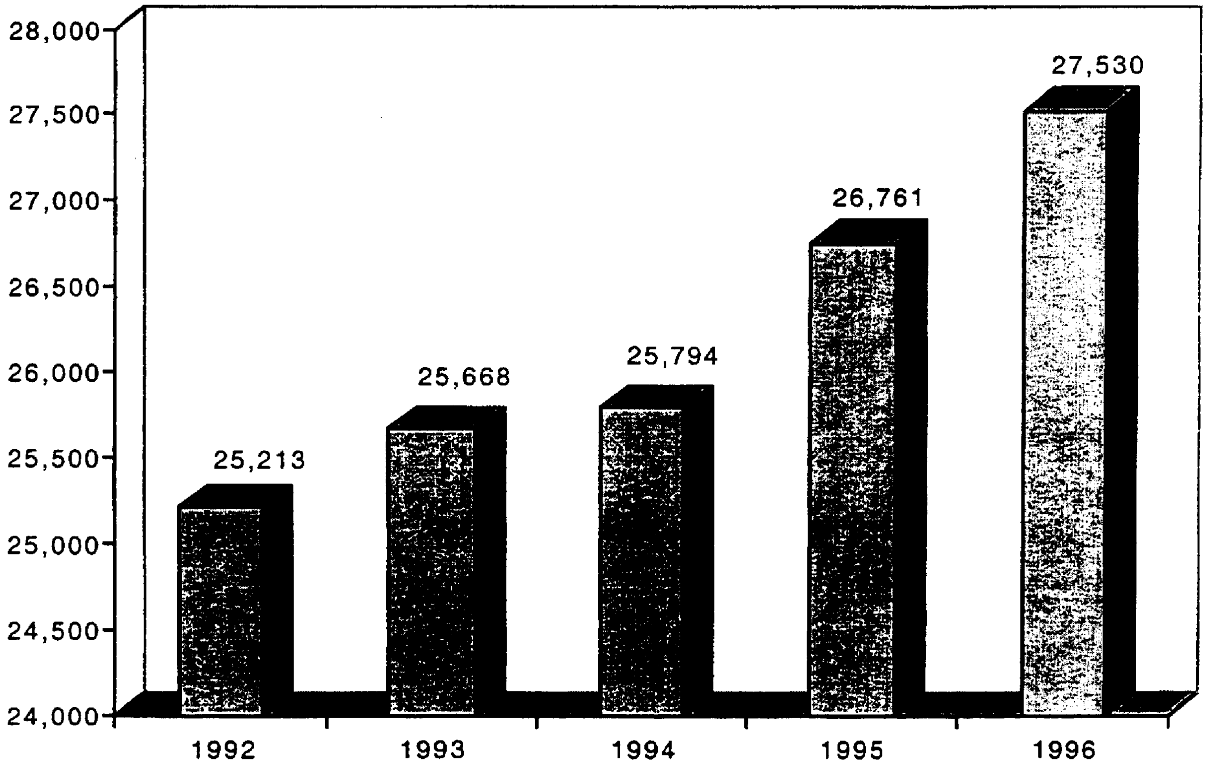
Completeness of Virginia Cancer Registry Data is Essential for Effective Surveillance, But There Are Concerns Regarding Completeness

The ultimate usefulness of any cancer registry is a function of the quantity and quality of its data. The completeness of cancer registry data is typically defined as the proportion of all cancer cases in the target population which appear in the cancer registry database. It is important to routinely measure the completeness of population-based cancer registries, because systematic bias in case reporting can result in the calculation of misleading and erroneous rates of cancer in the population.

Since 1990, VCR has been attempting to encourage full compliance among all cancer reporting sources statewide within the purview of the statutory obligation. However, during interviews with JCHC staff, VCR management stated its belief that compliance with statutory cancer reporting requirements is not nearly as high as it should be. According to VCR, not all physicians, clinics such as ambulatory surgery centers and radiation therapy centers, and independent pathology laboratories who are required to report cancer cases are doing so. Some of these providers, according to VCR, are not submitting any reports. Another concern is that some medical providers, particularly small hospitals without their own cancer registries, are failing to report all of the cancer cases diagnosed or treated within their facilities. In summary, VCR management is not convinced that the level of cancer case finding and reporting in Virginia is what it should be.

Figure 4

Number of New Cancer Cases Reported to Virginia Cancer Registry

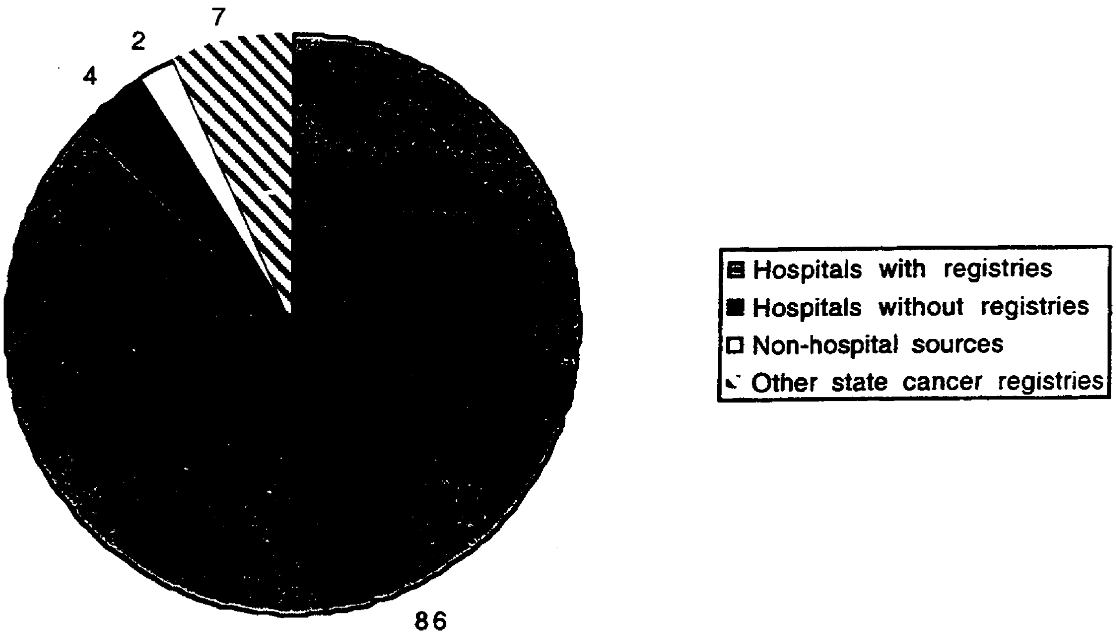


Source: Virginia Cancer Registry.

According to VCR management, and other individuals interviewed by JCHC staff, many cancer diagnostic and treatment procedures – such as those for melanoma and prostate cancer – are increasingly being provided in outpatient settings. Therefore, it is increasingly important for VCR to ensure that all medical providers are complying with the statutory reporting requirements. Otherwise, over the long term, VCR may be unable to accurately report the true incidence of cancer in Virginia.

Figure 5

Virginia Cancer Registry Reporting Sources (Percentage of Total Registry Cases From Each Source)



Source: Virginia Cancer Registry.

Knowledge of the extent to which the VCR is complete is based on a variety of different estimates that have been prepared over the past several years. These estimates have been prepared as part of the requirements of the NPCR, and through the central cancer registry certification process administered by NAACCR. These various estimates of VCR completeness have ranged from 77 percent to 87 percent (Figure 6).

States participating in the NPCR are expected to collect information on at least 95 percent of cancer cases diagnosed or treated in their state each year. As shown in Figure 6, the VCR has not yet achieved that level of completeness. VCR will have to reapply to CDC for NPCR funding, on a competitive basis, in the year 2000. Because this reflects over one-half of the VCR funding, it is important to show aggressive remedial steps.

One area which appears to be a particular challenge for VCR completeness is case reporting by hospitals that do not maintain their own cancer registries. These hospitals, which tend to have a relatively low volume of cancer patients, had a completeness rate of only 70 percent based on the 1997 revised NAACCR case completeness and data quality audit. This was in contrast to completeness rates of 92 percent and 94 percent for high and medium-volume hospitals, respectively.

Figure 6

Estimates of Virginia Cancer Registry Data Completeness

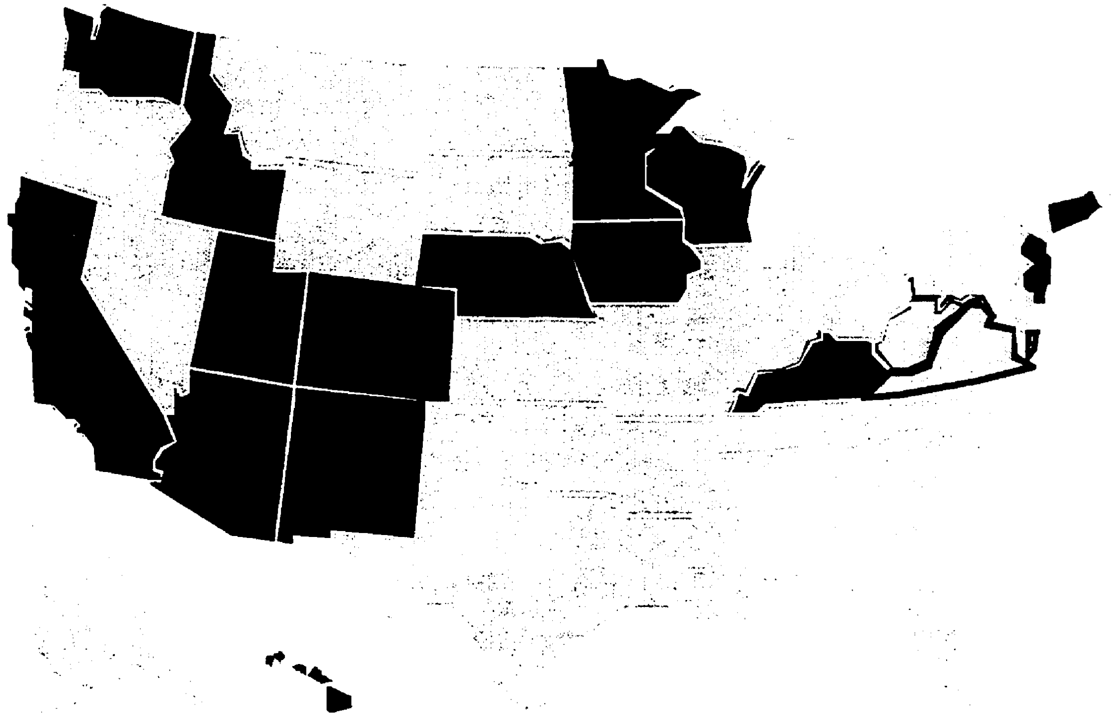
Percent Complete	Date of Estimate	Methodology
82.4%	July 1995	Case completeness and data quality audit performed by NAACCR. Based on review of 294 breast, cervix, and prostate cancer cases diagnosed in 1992. Sample drawn from 11 randomly selected hospitals representing low, medium, and high cancer caseloads.
85.8%	May 1997	Revision of the July 1995 NAACCR estimate.
76.9%	December 1998	Applies SEER cancer incidence to mortality ratio to the Virginia cancer mortality rate in order to estimate the expected Virginia cancer incidence rate for cases diagnosed in 1996. Expected rates are then compared to observed rates. Used by NAACCR as part of its central cancer registry certification process.
86.5%	March 1999	Computed by VCR for cases diagnosed in 1996. Age-specific cancer incidence rate reported by SEER for 1991-95 applied to Virginia population. Methodology prescribed by NPCR.

Source: JCHC staff analysis of VCR data and documentation.

NAACCR requires central cancer registries to achieve a 95 percent overall completeness rate in order to receive its highest level of certification. As of April 1999, 31 state cancer registries have been certified by NAACCR, 16 of which have achieved a 95 percent registry completeness rate (Figure 7). The purpose of NAACCR certification is to ensure that member registries are collecting useful and high quality data. The VCR has not yet achieved NAACCR certification. Although VCR management stated that there is disagreement among cancer registrars concerning the most valid method of evaluating cancer registry completeness, they acknowledge that national standards have not been met.

Figure 7

State Cancer Registries With 95 Percent Completeness Rate (States Shaded in Black Are At 95 Percent)



Source: Centers for Disease Control, and North American Association of Central Cancer Registries.

Death Clearance Process Helps Ensure Registry Completeness

NAACCR recommends that central registries perform a "death clearance" process as part of an overall effort to identify all cancer cases. A death clearance process involves matching all death certificates for a specific year against the entire cancer registry database. Death clearance enables a central cancer registry is to identify all deaths where cancer is mentioned as a cause of death, but which are not included in the registry. To the extent there are unmatched cancer deaths, the registry needs to follow-back to obtain the information needed to complete the incidence record, and to determine whether or not the case should be included in the central registry. For some cancer cases identified during death clearance, no additional information can be found beyond that which is recorded on the death certificate. From the point of view of cancer surveillance, such cases are missing information on many key variables. Death clearance also enables a registry to determine whether individuals previously reported to the registry are still alive.

In order to receive NAACCR certification, central cancer registries must perform a death clearance process on an annual basis, and must have less than five percent "death certificate only" cases for the year. Due to staffing limitations, VCR has not previously administered a death clearance process. However, VCR has been working for two years to develop the internal capability to perform this additional function, and reports being close to actual implementation.

The Virginia Cancer Registry Has Established Reciprocal Data-Sharing Agreements with Six Other Central Cancer Registries

Section 32.1-71 of the *Code of Virginia* authorizes the Commissioner of Health to enter into reciprocal data-sharing agreements with other cancer registries for the exchange of information. VCR currently has data sharing agreements with the following central cancer registries: Kentucky, Maryland, North Carolina, Washington, Washington, D.C., and West Virginia. The purpose of such agreements is, for example, for Virginia to provide Maryland with individual cancer case data that pertains to Maryland residents who were diagnosed or treated in Virginia, and vice versa. These agreements assist registries in enhancing the completeness of their data. VCR received 2,649 case reports for cancers diagnosed in 1996 as a result of these agreements.

VCR has attempted to negotiate an agreement with Tennessee but to date has been unsuccessful. According to VCR management, this failure is attributable to a legislative prohibition in Tennessee that has not yet been resolved. In the interim, VCR plans to ask the Tennessee cancer registry to determine how many cases they have for Virginia residents who were diagnosed and/or treated in Tennessee. This is important because VCR management believes that case reporting in Southwest Virginia may be artificially low. For example, while the age-adjusted cancer incidence rate for Virginia was 346.8 cases per 100,000 population, the rate for the Southwest health region was only 296.7. Within the Southwest health region, the age-adjusted incidence rate in the LENOWISCO health district was only 80.1 cancer cases per 100,000 population.

Satisfactory Data Quality is Essential to the Utility of Central Cancer Registries

A high degree of completeness is necessary, but not sufficient, for an effective central cancer registry. The quality of the data for reported cases is also essential. For example, the extent to which certain required data elements are missing, even though a new cancer case is reported, determines the ultimate effectiveness of the registry for cancer prevention and control purposes.

Overall, VCR management believes the quality of registry data to be high. In fact, the VCR has satisfied criteria for several of the of NAACCR standards for data quality, completeness, and timeliness necessary for certification (Figure 8). Nevertheless, there are some areas of potential concern regarding VCR data quality. According to analyses performed by VCR staff of cancer cases diagnosed between 1990 and 1996, there are several required data fields that are frequently left blank during the reporting process:

- 74% of cases had unknown occupation;
- 73% of cases had unknown industry;
- 93% of cases recorded unknown family history;
- 72% of cases had unknown history of alcohol use;
- 68% of cases had unknown history of tobacco use;
- 95% of cases had unknown dioxin exposure; and
- 94% of cases had an unknown code for service in the Vietnam War.

VCR shared these findings with hospital registrars during VCR's annual training conference in April 1999.

Another important dimension of data quality is timeliness. For certification purposes, NAACCR requires registries to identify all incident cases, conduct death clearance, identify and consolidate duplicate cases, and resolve all errors detected through automated edit processes within 23 months from the close of a diagnosis year. The NPCR requires publication of an annual report of cancer incidence by a central cancer registry within 12 months of the end of a diagnosis year. VCR has had difficulty complying with this requirement in the past. The most recent annual report of cancer incidence was for cases diagnosed between 1990 and 1994. However, this report was not published until January 1998. Since then, there have not been any additional annual reports of overall cancer incidence released by VCR. However, according to VCR management, a combined report for 1995 and 1996, as well as a separate report for 1997, are expected to be published prior to the end of 1999.

Figure 8
Virginia Cancer Registry Adherence to NAACCR Certification Standards

Registry Element	Gold Standard	Silver Standard	Actual Measure	Standard Achieved
Completeness of case ascertainment	95%	90%	76.9%	Not Achieved
Missing/unknown "age at diagnosis"	<=2%	<=3%	0%	Gold
Missing/unknown "sex"	<=2%	<=3%	0%	Gold
Missing/unknown "race"	<=3%	<=5%	2%	Gold
Missing/unknown "State/Province & county"	<=2%	<=3%	0%	Gold
Death certificate only cases	<=3%	<=5%	N/A	Not Achieved
Duplicate primary cases	<=1 per 1000	<=2 per 1000	3.1 per 1000	Not achieved
Passing EDITS	99%	97%	100%	Gold
Timeliness	Data submitted within 24 months of close of diagnosis year			Gold

Source: NAACCR Registry Certification on Quality, Completeness & Timeliness of 1996 Data, Summary of Certification Measures.

The Virginia Cancer Registry Has Not Collected Follow-Up Data on Cancer Patients From Hospital Cancer Registries For Six Years

Virginia's cancer reporting regulations (12 VAC 5-90-180) require that "cancer programs conducting annual follow-up on patients shall submit follow-up data monthly in an electronic format approved by the Virginia Cancer Registry." The American College of Surgeons, as part of its approval of hospital cancer programs, requires hospitals to collect annual follow-up data on cancer patients. Hospitals with cancer registries are collecting these follow-up data as required. However, VCR has not actually collected these data from hospitals for its use, as required by state regulation, for approximately six years.

This was a decision of VCR management, arising out of concern that it lacked sufficient staff to effectively process all of the follow-up data that was being reported by hospitals, in addition to an increasing backlog of reports of newly diagnosed cases. At the time, all reports were on paper and were manually entered into a database. With the intention of collecting follow-up data on those cases at some point in the future, VCR management chose to focus its restricted resources on ensuring that high quality standards were maintained. The lack of such follow-up data limits the ability of VCR to conduct cancer patient survival analyses. For example, VCR is currently unable to compute an overall Virginia cancer survival rate. According to the American Cancer Society, the five-year national relative survival rate for all cancers combined is 60 percent.

VCR management reports that it will begin to address this issue with hospitals in the near future. Staffing issues within VCR to ensure the additional data are processed, and software revisions on the part of hospitals to facilitate reporting of new information on existing cases, need to be addressed in order to resolve this issue. VCR management does state that it is not unusual for central cancer registries to have to defer on the objective of timely survival analysis due to staffing constraints and/or software difficulties.

VCR Plans to Improve Data Completeness and Assure Quality

The VCR has only recently emerged from a fairly extended period of time during which it had accrued a substantial backlog of processing reported cases. The backlog was particularly severe for cases diagnosed from 1993 to 1996. That backlog has since been eliminated as the result of a concerted effort by VCR staff. However, in focusing much of its attention on eliminating this backlog, VCR has yet to perform several of the types of functions routinely conducted by many other central cancer registries, particularly those certified by NAACCR.

VCR management does plan to begin implementing several new functions in the near future, at least to the extent it is able given its available staff resources. First, VCR plans to implement a routine case finding audit program. Under this program, VCR staff will visit selected medical providers to ensure that 1) all cancer cases have been reported and 2) all required data fields for previously reported cancer cases have been accurately completed. The initial medical providers to be scheduled for audits will likely be hospitals without their own cancer registries and with a relatively low volume of cancer cases. VCR staff received training from CDC in 1998 for on-site case finding and data reabstracting reviews. Ideally, once the case finding audit program is fully implemented, VCR will be able to evaluate its case ascertainment completeness rate in order to update prior estimates of completeness.

VCR also plans to implement an annual death certificate clearance and follow-back process. VCR is in the process of working with its software vendor to make the necessary programming changes to implement this new function. As previously mentioned, NAACCR certification standards allow for no more than five percent "death certificate-only" cases. However, NAACR anticipates that this percentage will be substantially higher when a central registry first initiates a death clearance process. Consequently, VCR expects a ten-percent death certificate-only rate upon implementation of this new function.

VCR management also reports several other significant activities designed to improve the completeness and quality of registry data. These include the geocoding of registry data, using census tract of residence, to support new types of analyses of cancer incidence; and the use of hospital discharge data from Virginia Health Information as part of case finding activities. In addition, VCR has made efforts to notify physicians of the new reporting requirements. Information has been placed in publications of the Medical Society of Virginia and state Board of Health. VCR also plans to mail information concerning the new reporting requirements to all of the state's licensed physicians.

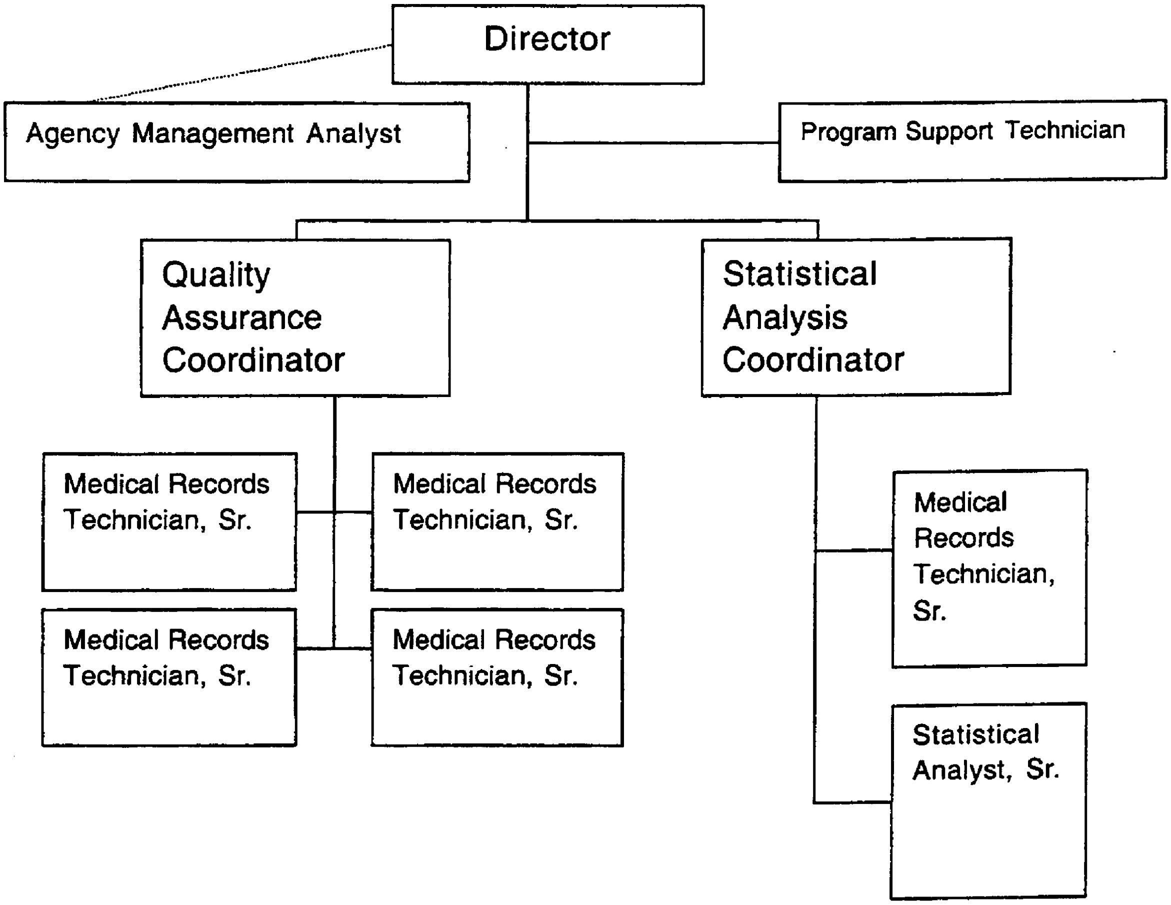
Virginia Cancer Registry Staffing Has Increased in Recent Years, But Concerns Persist Over Staffing Levels

The Virginia Cancer Registry is administered by staff within the Virginia Department of Health's Office of Epidemiology, Division of Surveillance and Investigation. The VCR's FY 1999 operating budget is $591,741, of which 55 percent is obtained from federal funds through

CDC's National Program of Cancer Registries. According to federal maintenance of effort requirements, Virginia must spend at least $253,000 in state funds for VCR to continue to receive federal funding. State FY 1999 general fund appropriations for the VCR are $261,393.

Figure 9

Virginia Cancer Registry Organization Chart



Notes: Agency management analyst devotes 50 percent of his time to VCR. One of the medical records technician, sr. positions in the quality assurance unit, as well as the statistical analyst, sr. position, were vacant as of June 1, 1999.

Source: JCHC staff graphic based on Virginia Cancer Registry documentation.

The VCR currently has 10.5 staff positions (Figure 9). Federal funds are used to support 4.5 of VCR's 10.5 staff positions, including the director, quality assurance coordinator, and statistical analysis coordinator. The quality assurance unit performs a number of automated and manual-editing functions designed to ensure the accuracy of reported data. The statistical analysis unit is responsible for responding to public requests for information, and for conducting data analysis as part of VCR-sponsored studies.

Following an executive branch hiring freeze several years ago, VDH contracted with Virginia Commonwealth University (VCU) in order to fill several VCR positions. Currently, four of the VCR staff positions are actually VCU contract positions. Through use of the VCU contract positions, total VCR staff positions have increased from 5 in FY 1995 to 10.5 in FY 1999.

Several individuals interviewed by JCHC staff expressed various concerns about VCR staffing. For example, several other state cancer registries have field staff who work on-site with medical providers in order to ensure complete, accurate cancer reporting (Figure 10). A representative of NAACCR stated that while VCR has a strong staff, the lack of field staff dedicated to this effort is a relative weakness. CDC has recommended that VCR hire a staff person to perform cancer case finding activities in smaller hospitals with low volumes of cancer patients, and without their own cancer registries. Such individuals, typically referred to by cancer registrars as "circuit riders," personally review medical charts in order to collect the required cancer reporting data. However, CDC has stated that federal funds cannot be used to support such positions. According to CDC officials, federal funds should not be used to, in effect, relieve medical providers of the need to personally comply with cancer reporting requirements. Nevertheless, CDC does not object to state funds being used for this purpose.

Other staffing issues raised by VCR management include inadequate position classifications for the medical record technician, senior positions in the quality assurance unit. These are the staff who will be required to perform the new case finding audit function that VCR plans to implement. These positions are a grade eight. According to VCR management, this relatively low pay grade makes recruitment difficult, since VCR prefers to hire only individuals who are certified tumor registrars. Another staffing issue concerns an insufficient number of medical record technician, senior positions in the quality assurance unit. The current average cancer report caseload per employee is approximately 6,000 cases. According to VCR staff, a more reasonable caseload would be 4,000 cases. To achieve that caseload, an additional two medical record technician, sr. positions would need to be established within VCR.

Figure 10

Staffing Levels of Central Cancer Registries in Virginia and Neighboring States

State	Total Staff	Field Staff	Annual Reportable Cancer Cases
Kentucky	13	3	20,000
Maryland	12.5	4.5	23,700
North Carolina	21	5	36,000
Virginia	10.5	0	27,530
West Virginia	8	2	11,000

Note: Tennessee did not respond to survey.
Source: JCHC staff survey of other central cancer registries.

IV.

Public Access to Virginia Cancer Registry Data

The Commissioner of Health is Authorized by Law to Release Virginia Cancer Registry Data in Certain Circumstances

Section 32.1-70 of the *Code of Virginia* states that information submitted to the VCR shall be kept confidential. According to the statute, "No publication of any such information shall be made except in the form of statistical or other studies which do not identify individual cases." Section 32.1-41 of the *Code of Virginia*, states that "The Commissioner or his designee shall preserve the anonymity of each patient and practitioner of the healing arts whose records are examined" as part of the VDH disease surveillance function. However, according to §32.1-41, "the Commissioner, in his sole discretion, may divulge the identity of such patients and practitioners if pertinent to an investigation, research, or study. Any person to whom such identifiers are divulged shall preserve their anonymity."

Confidentiality of Virginia Cancer Registry Data Appears to Be Adequately Protected

The VCR maintains specific procedures to ensure the confidentiality of patient data (1) when submitted from reporting facilities, (2) once within the registry, and (2) when released to external researchers approved by the Commissioner of Health. For example, according to VCR confidentiality guidelines:

- All paper files received for cancer patients are maintained in a storage area when not in use.

- The registry database is maintained on a secure computer server with firewall protections that allow no external logins. Personal computer access to the server and registry data is limited to VCR staff with approved network accounts and current password authority. Confidential data will not be left on the computer screen when VCR staff leave their desk during the day.

- The confidentiality guidelines are discussed with each VCR employee, and each is required to sign a statement of agreement to adhere to the confidentiality policy. Any unauthorized release of data by VCR staff, either oral or written, shall result in immediate disciplinary action and may be cause for termination of employment.

The VDH has developed guidelines for the release of confidential patient information. An institution or individual involved with "medical, epidemiological, health care, or other cancer-related research" may receive protected data if the Commissioner determines that the research "will benefit the public health of Virginians" and that the recipient of the information can and will maintain the anonymity of patient and provider identities. Principal investigators wishing access to specific VCR records or data items are required to submit a written request explaining why confidential information is needed and how it will be used, and specifying how confidentiality will be protected. This is consistent with provisions of federal law governing the NPCR, which require registries to develop a "means by which confidential case data may in accordance with State law be disclosed to cancer researchers for purposes of cancer control, prevention, and research."

All VCR data recipients are required to sign a confidentiality agreement, stating that the individual will take "every precaution to preserve the anonymity of patient and practitioner identities." A data recipient agreement must also be signed, among whose provisions are those specifying that:

- identifying information will not be used as a basis for legal, administrative, or other actions which may directly affect those particular individuals or establishments as a result of their specific identification; and

- identifying information will not be distributed to anyone else and will not be used for any project other than the one given specific approval by the Commissioner of Health.

According to VCR management, there has never been any unauthorized release of confidential information from the registry. Based on interviews with CDC officials and NAACCR representatives, central cancer registries across the country have an exceptional record of safeguarding the confidentiality of their data. The Virginia Attorney General's Office had indicated that the confidentiality safeguards in place at VCR are similar to those implemented by other State agencies.

Confidentiality Safeguards Within Reciprocal Data-Sharing Agreements

Section 32.1-71 of the Code of Virginia authorizes the Commissioner of Health to enter into data-sharing agreements with other states only, "upon the provision of satisfactory assurances for the preservation of the confidentiality of such information...." With the exception of the agreement with Washington, all of the data-sharing agreements require that exchanged data of the VCR shall be maintained in the other state under the confidentiality provisions set forth in the *Code of Virginia.* However, the agreement with Washington provides that a cancer patient's identify or identifying information obtained from another registry shall not be released for research or other purposes without the express permission of the other party. In these cases, the researcher or requestor is to be referred to the registry that provided the original report.

There Are Numerous Requests for Virginia Cancer Registry Data

From January 1996 through May 1999, VCR received a total of 347 data requests. Requests for aggregate data comprised the vast majority, 93 percent, of the total. As illustrated in Figure 11, data requests to VCR come from a wide range of sources. For example, requests for aggregate cancer statistics are often received from students, consultants and even reporters.

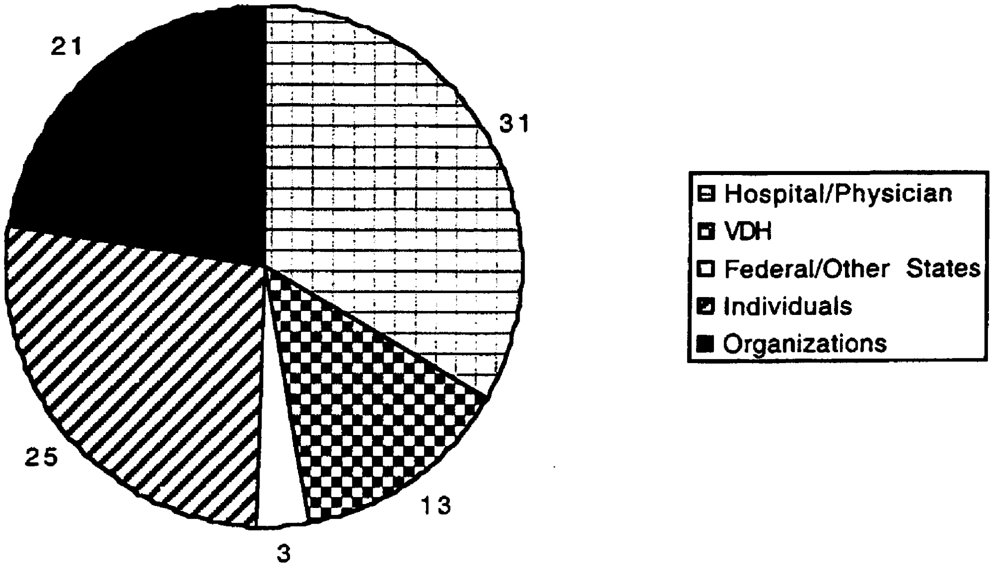
Requests for individual, patient-specific data are either for 1) researchers seeking information on various patient cohorts; or 2) hospital or other state central cancer registries seeking follow-up information on a limited number of individual patients. None of the requests for individual, patient-specific data made since 1996 have been denied by VCR. However, some researchers have been made to revise or clarify their request before approval was granted.

The Virginia Cancer Registry Receives Inquiries Concerning Perceived "Cancer Clusters" in Certain Localities

Over the past two years, VCR has received about 24 telephone calls from citizens concerning perceived excessive numbers of cancer cases in their localities. Upon receipt of such inquiries, VCR staff analyze available data in order to address the caller's concerns. According to VCR management, it has never had a cancer cluster inquiry in which the reported cases have been proven to be the result of identifiable factors, such as environmental or biological conditions, that were unique to a specific location.

Figure 11

Sources of Requests for Virginia Cancer Registry Data During 1998 (104 Total Requests)



Note: Individuals include citizens, students, reporters and consultants. Organizations include colleges/universities, corporations, and non-profit organizations.

Source: JCHC staff analysis of Virginia Cancer Registry data.

The Mandatory Reporting of Patient Identifying Information is Essential to Cancer Registry Effectiveness

An individual's right to privacy is a critically important principle. However, within the broad realm of public policy this principle is, in practice, often balanced against others – such as the need to protect and improve individual and public health. Over the past year, the VCR has responded to correspondence from a few individuals who have expressed concerns, based primarily on issues of privacy of personal information, regarding the mandatory reporting of information to the state registry. Three of the specific concerns that were raised with VCR concerned 1) the registry's need for personal identifying information; 2) the desirability of allowing cancer patients to provide their consent prior to having their personal information reported to the VCR, and 3) a lack of notification to cancer patients concerning the existence of the Virginia Cancer Registry.

According to VCR management, there are numerous reasons why personal identifiers are needed. One of the most important involves data management. Since many cancer patients receive care from a number of different medical providers, VCR has to be able to determine if a reported person has been previously reported and to consolidate information reported from different sources. Without personal identifiers, estimates of cancer incidence can not be accurately determined. For example, the 130,966 cancer cases reported to VCR from 1992-1996 were actually consolidated from 143,646 reports from multiple sources. Furthermore, VCR management envisions problems with devising unique personal identifiers other than name or social security number. First, VCR has cited the complexity of administering a system that would assign truly unique numbers. Second, a numbering system is believed to be impractical because numbers would not always follow every patient through the health care system and providers would not have access to each unique identifier or to be able to report it consistently.

In terms of informed consent of cancer patients prior to reporting their personal information, VCR management stated that it would inevitably result in a number of cancer patients "opting-out" of the registry. Consequently, the registry would become "inaccurate, possibly misleading, and probably of little value." According to VCR management, "It is not possible to collect data for population-based statistics and public health purposes if informed consent is required." A representative of NAACCR interviewed by JCHC staff stated that "informed consent will bring public disease surveillance to a halt."

To the extent that Virginians who are diagnosed with cancer are aware of the existence of the VCR, it is a result of the actions of their medical care providers. One hospital-based cancer registrar interviewed by JCHC staff reported that a few hospitals in Virginia have mechanisms in place, or plan to soon implement them, to notify cancer patients of the fact that their case is being reported to the VCR. However, it is believed that such notification mechanisms are the exception, and not the rule. From an ethical point of view, VCR management does not oppose the concept of improved notification of cancer patients concerning cancer registry reporting requirements. However, it does not feel that VCR should be required to provide such notification itself. Rather, VCR management believes that notification is better provided as part of communication between physicians and patients.

The state of Oregon has a statutory requirement for notification of cancer patients concerning registry reporting, the purposes of the registry and the protection of confidentiality. Information that must be provided to cancer patients includes:

- statutory requirements for reporting of every newly diagnosed cancer case;
- the specific types of information required to be reported;
- that the information is used to understand how cancer affects the population in Oregon, to design and implement prevention and control programs, and for research;
- that the information is confidential and can not be released unless very strict requirements, as provided by law, are met;
- if those specific legal requirements are met, researchers may be allowed to contact patients to offer them the opportunity to participate in research projects on a purely voluntary basis; and
- that the researcher must first consult with the patient's physician regarding participation in a research project, unless the patient specifies to the registry that their name never be released for any research purpose; or that the researcher may contact them directly about participation in research projects.

According to the Oregon statute, patient notification is required to be provided within one month of receipt of the case report by the registry. The state cancer registry is required to provide this notification unless a health care facility or provider notifies the registry that it will routinely assume notification responsibilities for all patients. For such facilities or providers, the state registry is required to annually reconfirm that continued notification responsibility is desired. The costs of providing such notification have been approximately $1 per patient.

According to individuals interviewed by JCHC staff, there are some potential negative consequences of mandatory notification mechanisms. First, it is possible the notification will result in a demand by the cancer patient that his or her information not be reported. It is also described as possible that some of the individuals so notified will not have actually been apprised of their diagnosis by their physician. For example, a son or a daughter may have requested a physician not to inform an elderly parent of their diagnosis.

The Virginia Cancer Registry is One Component of a Broader Cancer Prevention and Control Planning Effort Within the Commonwealth

Cancer control encompasses all actions taken to reduce the impact of cancer. Cancer control may be described in terms of six components:

- Primary prevention – actions taken to reduce human exposure to agents that may cause cancer;
- Screening – actions directed towards asymptomatic people in order to identify those at high risk for cancer for whom some program of continuing screening, diagnosis, and/or therapy may reduce subsequent morbidity or mortality;
- Early diagnosis – actions taken to increase the probability that a person with cancer will have that cancer diagnosed at a stage when treatment is likely to result in a cure;
- Treatment – actions taken for a patient with cancer which have the cure of cancer as the objective;
- Rehabilitation – actions taken for a cancer patient to restore physical, mental, and social functioning; and
- Palliative care – actions taken for a patient who has cancer that can not be cured, which have continuing maximization of the patient's physical, mental, and social well-being as their objective.

Recent national data suggest that some progress is finally being made toward reducing the public health burden posed by cancer:

- In 1995, the year 2000 healthy families' initiative target for total cancer death rates was achieved with 130 reported cases per 100,000. African-American cancer rates have decreased from the 1990 baseline of 182 per 100,000 to 172 in 1995, thereby exceeding the 2000 target of 175 per 100,000.
- After increasing from 1973 to 1990, incidence rates for all cancer sites combined decreased 0.9 percent per year from 1990 to 1996. The peak year was 1992; from 1992 to 1996 the rate decreased 2.2 percent per year. However, the overall decrease masks substantial differences in cancer rates between the sexes and even bigger ones between ethnic groups. Continued higher incidence and death rates among some racial

and ethnic groups suggest that some populations may not have benefited equally from cancer prevention and control efforts.

The VDH Division of Chronic Disease Prevention and Nutrition is currently leading an effort to develop a state plan for the prevention and control of cancer. The primary purpose of the plan will be to guide cancer prevention and control efforts within the state during the years 2000 –2005. Additional purposes include (1) to identify and establish working relationships between VDH and other agencies/individuals statewide to plan, implement, and evaluate cancer prevention and control strategies; and (2) to apply for categorical funding from federal and other sources to implement the strategies proposed by the plan. VDH is working with the Cancer Plan Advisory Committee (CPAC) to develop the planning document. CPAC is comprised of approximately 36 individuals, and includes representatives from public and private cancer prevention and control organizations, as well as spokespersons for target populations.

According to preliminary CPAC planning documents examined by JCHC staff, the VCR's role in the overall plan is seen as helping to achieve the following cancer surveillance objectives:

- collect complete, accurate, and timely data on cancer incidence;
- describe the epidemiology of cancer incidence in Virginia;
- evaluate the cancer collection data functions in Virginia;
- evaluate the cancer data analysis activities in Virginia; and
- evaluate the utility of disseminated surveillance data to provider, community, and health organizations.

Overall, the VCR appears to be well managed and to serve a highly useful purpose. Furthermore, the VCR is held in high regard by its many stakeholders. In order to ensure that the VCR is well positioned to effectively contribute to the state's comprehensive approach to cancer prevention and control, VCR needs to effectively address issues pertaining to the completeness and quality of its data. The statutes that are currently in effect in Virginia concerning cancer reporting appear to be adequate, from a public policy perspective. It appears that VCR needs to focus its efforts to work more closely with providers to ensure that existing reporting requirements are complied with. In order to effectively do so, VCR would benefit from some additional, but carefully targeted, staff resources.

While performing its cancer surveillance functions, VCR must remain cognizant of the need to uphold the concept of confidentiality in all respects. While VCR confidentiality policies and procedures appear to be effective, there may be room within the process for VCR and medical providers to promote greater awareness of the cancer registry reporting requirements, and benefits, to cancer patients throughout the state.

V.
Policy Options

The following policy options are offered for consideration by the Joint Commission on Health Care. However, these policy options do not represent the entire universe of options that the Joint Commission on Health Care may wish to pursue with regard to the Virginia Cancer Registry. Options II through VI are not mutually exclusive; the Joint Commission on Health Care could choose to implement any or all of these policy options.

Option I: Take No Action

Option II: Introduce legislation, and an accompanying budget amendment, requiring the Virginia Cancer Registry to implement a mechanism – based on the use of dedicated field staff - for ensuring that all cancer cases are accurately reported.

Option III: Introduce legislation requiring the Virginia Cancer Registry to annually perform a death clearance and follow-back process.

Option IV: Introduce a joint resolution requesting the Virginia Cancer Registry to take all actions necessary to ensure that follow-up data on cancer patients is collected from hospitals, processed in a timely manner, and used to support cancer patient survival analysis. The joint resolution should require the Virginia Cancer Registry to report to the Governor and the General Assembly concerning its progress prior to the 2002 General Assembly Session.

Option V: Introduce a budget amendment (language) directing the Department of Personnel and Training, with technical assistance from the Virginia Department of Health, to conduct a compensation and position classification study of the Virginia Cancer Registry, with a focus on the medical record technician, senior positions.

Option VI: **Introduce legislation, and an accompanying budget amendment, requiring the Virginia Cancer Registry, in cooperation with medical providers, to develop and implement a mechanism for notifying all cancer patients in Virginia of the purpose, objectives, and requirements of the Virginia Cancer Registry, and the confidentiality policies and procedures that have been implemented, as part of the reporting process.**

APPENDIX A

HOUSE JOINT RESOLUTION NO. 524

Directing the Joint Commission on Health Care to study Virginia's Statewide Cancer Registry.

Agreed to by the House of Delegates, February 5, 1999
Agreed to by the Senate, February 18, 1999

WHEREAS, the American Cancer Society estimates that eight or more million Americans are cancer survivors or are being treated for cancer; and

WHEREAS, the 1998 estimate of 1.23 million new cases of cancer does not include localized carcinomas or the approximately 1 million cases of diagnosed basal and squamous cell skin cancers; and

WHEREAS, one out of four deaths in 1998 in the United States is attributable to cancer, with an estimated 564,800 Americans dying of cancer per year; and

WHEREAS, Virginia has collected data on cancer incidence since 1950; and

WHEREAS, federal law approved in 1992 established the National Program of Cancer Registries within the Centers for Disease Control and Prevention for the purpose of improving states' existing cancer registries; and

WHEREAS, Virginia's law and program have evolved over the last 48 years and have been enhanced to meet the federal goals and requirements; and

WHEREAS, cancer surveillance is an important tool in developing a comprehensive and unified scientific and public health mechanism for effective cancer prevention and detection; and

WHEREAS, although the Commonwealth is to be commended for its early recognition of the need for cancer surveillance data, there is reason to believe that the collection, collation, and use of such data could be significantly improved or revised to provide greater benefits to the citizens of Virginia; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care be directed to study Virginia's Statewide Cancer Registry.

In conducting its study, the Joint Commission shall examine the effectiveness of the Statewide Cancer Registry as established in Article 9 (¤ 32.1-70 et seq.) of Chapter 2 of Title 32.1 to determine the:

1. Completeness of the data, i.e., whether all necessary reporting sources are required to submit data to enable the registry to collect comprehensive cancer surveillance data.

2. Timeliness of the data reporting, collation, and analyses.

3. Manner and thoroughness of the data collation, including, but not limited to, any geographic and population subcomponents.

4. Uses of the data for prevention, intervention, and treatment analyses and strategies, including education of the public, medical and health services research, treatment evaluations, and public health intervention and prevention.

5. Access to the data by experts for research purposes and by the public for educational purposes.

6. Confidentiality of the data in both statistical and individual form and whether individual data should be available to any researchers, the subject of the data or the subject's family and, if so, the scope of the information to be disclosed and the circumstances for disclosure.

7. Legal basis for the registry and whether this legal authority as reflected in Title 32.1 of the Code of Virginia is sufficient to serve the Commonwealth in monitoring cancer incidence and mortality, guiding cancer control planning and evaluation, assisting in prioritizing health resource allocations, advancing medical and public health research, and contributing to the development of both a Virginia and a national cancer control strategy.

8. Principles and practices currently in use for cancer control in Virginia and the necessary revisions to these strategies to improve the synergism, sustainability, and effectiveness of the Commonwealth's cancer control efforts.

All agencies of the Commonwealth shall provide assistance to the Joint Commission, upon request.

The Joint Commission shall complete its work in time to submit its findings and recommendations to the Governor and the 2000 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

APPENDIX B

CHAPTER 803

An Act to require a study of the cancer registry.
[S 942]
Approved March 29, 1999

Be it enacted by the General Assembly of Virginia:

1. § 1. Cancer registry to be studied.

The Joint Commission on Health Care shall study the cancer registry, including an analysis of the exchange of patient-identifying information pursuant to reciprocal data-sharing agreements with other cancer registries and confidentiality protections for patient data. In its study, the Joint Commission shall examine the potential for inappropriate disclosure of patient data as a result of such data exchange, whether the registry should be required to obtain the patient's consent, and any appropriate penalties for breach of confidentiality.

APPENDIX C

JOINT COMMISSION ON HEALTH CARE

SUMMARY OF PUBLIC COMMENTS:
CANCER REGISTRY STUDY (HJR 524/SB 942)

Organizations Submitting Comments

A total of four organizations and individuals submitted comments in response to the HJR 524/SB 942 report on the cancer registry.

- Virginia Department of Health
- American Cancer Society
- Robert J. Falconer, M.D, Member of the Virginia Cancer Registry Advisory Board, and Professor Emeritus at Eastern Virginia Medical School
- George T. Keller

Policy Options Included in the HJR 524/SB 942 Issue Brief

Option I: **Take No Action**

Option II: **Introduce legislation, and an accompanying budget amendment, requiring the Virginia Cancer Registry to implement a mechanism – based on the use of dedicated field staff - for ensuring that all cancer cases are accurately reported.**

Option III: **Introduce legislation requiring the Virginia Cancer Registry to annually perform a death clearance and follow-back process.**

Option IV: **Introduce a joint resolution requesting the Virginia Cancer Registry to take all actions necessary to ensure that follow-up data on cancer patients is collected from hospitals, processed in a timely manner, and used to support cancer patient survival analysis. The joint resolution should require the Virginia Cancer Registry to report to the Governor and the General Assembly concerning its progress prior to the 2002 General Assembly Session.**

Option V: **Introduce a budget amendment (language) directing the Department of Personnel and Training, with technical assistance from the Virginia Department of Health, to conduct a compensation and position classification study of the Virginia Cancer Registry, with a focus on the medical record technician, senior positions.**

Option VI: **Introduce legislation, and an accompanying budget amendment, requiring the Virginia Cancer Registry, in cooperation with medical providers, to develop and implement a mechanism for notifying all cancer patients in Virginia of the purpose, objectives, and requirements of the Virginia Cancer Registry, and the confidentiality policies and procedures that have been implemented, as part of the reporting process.**

Overall Summary of Comments

The comments were generally favorable. Options II and V were clearly supported by all of the respondents. Options III, IV, and VI received varying levels of support and opposition. None of the commenters supported Option I.

Summary of Individual Comments

Virginia Department of Health

E. Anne Peterson, M.D., M.P.H., Acting State Health Commissioner, commented in support of Options II and V, and to a lesser extent Option VI. Concerning Option II, Dr. Peterson stated that "the ability to deploy field staff would be very favorable to VDH...The cancer registries in all our neighboring states employ field staff who visit hospitals and find cancer cases that need to be registered." In terms of Option V, Dr. Peterson commented that "VDH welcomes a study of the classification of the registry staff positions. The management of the registry has long felt that the scope and complexity of the duties of these positions are far greater than is reflected in their current compensation." With regard to Option VI, Dr. Peterson stated that "the Agency supports the concept of notifying cancer patients about the state cancer registry. We believe, however, that this would be more acceptable to patients if it were part of the provider-patient communication surrounding the diagnosis of cancer, rather than an impersonal communication from the Virginia Cancer Registry...However, if legislation were introduced and funds were available, the registry would be willing to develop a brochure that provides information about the purpose of the registry and the procedures followed to protect the confidentiality of the data."

Dr. Peterson stated that Options III and IV are unnecessary because the Virginia Cancer Registry is already implementing a death clearance and follow-back process (Option III), and because it plans to implement follow-up data collection and survival analyses (Option IV.)

Finally, Dr. Peterson requested that the Joint Commission on Health Care consider two additional policy options not included in the issue brief. First, "it may be beneficial to include in 32.1-71 of the *Code of Virginia* cross-references to 32.1-27, regarding penalties, and 32.1-41, regarding the confidential nature of data and data release issues." Second, "In order to reduce the burden on individual physicians required to report, an amendment to Section 32.1-70 could enable them to report cases through a hospital registry. This benefits physicians by relieving their need to devote staff resources to reporting to the state registry, and it would lead to more complete and better quality case reports to the VCR."

American Cancer Society

The American Cancer Society commented in support of Options II and V. Option II "would go a long way to facilitating all the goals of the Virginia Cancer Registry...." Option V "would facilitate greatly the recruitment of highly skilled personnel needed to supplement the current excellent, but understaffed, organization within the Virginia Department of Health." According to the American Cancer Society, Options III and IV "only outline what is already an action plan in progress in the Virginia Cancer Registry and hardly requires legislative action of the type outlined...." Concerning Option VI, the American Cancer Society commented that while it had "some attractive public relations features, in view of the questions raised about these matters by very few individuals, we fear the cost of implementing this option would be great and would detract from fulfilling policy options II and V."

Robert J. Falconer, M.D., Member of the Virginia Cancer Registry Advisory Board, and Professor Emeritus at Eastern Virginia Medical School

Dr. Falconer commented in support of Options II through VI. Dr. Falconer stated that he did not consider any of the options to be mutually exclusive, although "a merger of them would probably be effective." According to Dr. Falconer, "it is evident that major defects in the Virginia Cancer Registry are recognized and must be eliminated for the Registry to achieve the goal of its founders in 1970." Dr. Falconer also stated that in terms of compliance with reporting requirements, "Hospital compliance is good. The need for compliance by independent laboratories is the most difficult barrier and demands a stronger enforcement mode."

George T. Keller

Mr. Keller commented in support of Options II through VI. Mr. Keller stated that he would like to see the Virginia Cancer Registry become certified by the North American Association of Central Cancer

Registries. Mr. Keller also stated that "the staff of the Virginia Cancer Registry needs to be increased so that they can do the work mandated by the state...There has to be a field staff if this Virginia Cancer Registry is going to be successful."

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