

Nuclear Regulatory Commission

Cancer Incidence Feasibility Study

ORISE
10/22/2009

CANCER INCIDENCE FEASIBILITY STUDY

OBJECTIVES

The U.S. National Cancer Institute (NCI) 1990 report “Cancer in Populations Living near Nuclear Facilities” included very limited analyses of cancer incidence. Cancer incidence data of sufficient quality, covering a suitable span of years to warrant analysis of cancer incidence was available for only four facilities. As pointed out in the 1990 report, survivorship from thyroid and breast cancer and from childhood leukemia was sufficiently high at that time so that the results of the mortality analysis for these cancer endpoints could have been misleading. In the 20 years since that study was completed, the advances made in cancer survival, in cancer incidence reporting, and in geographical information systems (GIS) as well as the positive association found in other countries, between childhood leukemia incidence and living in the vicinity of nuclear facilities warrant the reevaluation of the feasibility of doing a cancer incidence study.

APPROACH

Both county and spatial analyses should be carried out using methodology similar to that proposed for the update of the 1990 mortality study. County and spatial analyses can provide complementary results. While the county analysis can include time prior to 1990, the spatial analysis will be limited to 1990 onward since population data by census tract and block number that are needed to calculate rates are only available since the 1990 census. The same set of nuclear facilities should be included with the study counties and control counties used in the mortality analyses. Using similar methodology for both the mortality and incidence studies will facilitate evaluation of the similarity of results as well as increase the efficiency of the work by reusing the same study and control counties and same area definitions for the spatial analyses. While results for some cancer sites would be expected to be different because of survivorship after diagnosis (e.g., thyroid cancer), the results for those cancer sites with a limited survival after diagnosis (e.g., pancreatic cancer) would be expected to be similar in the mortality and incidence studies.

AVAILABILITY OF CANCER INCIDENCE DATA

Critical to addressing the question of whether or not the population living near Nuclear Regulatory Commission (NRC)-licensed nuclear reactors is at increased risk of developing cancer is the availability of cancer incidence data. Incidence data will be required from 35 states. These states currently or previously had a reactor located in them, or application has been made for future construction of a reactor. The data items needed to carry out a cancer incidence study are as follows: county at diagnosis for a county level analysis; address at diagnosis for a spatial analysis; and race, sex, birth date, date of diagnosis, and primary cancer site for both types of analysis. A national repository for cancer incidence data, similar to the repository for mortality data that resides in the National Death Index, does not currently exist. The 35 states of interest all have tumor registries that have been collecting cancer incidence data for varying period of time. In 16 states the cancer registry began before 1990, in 16 states between 1990 and 1999, and in 3 states on or after 2000 (Table 1).

TABLE 1
State Registry Data

State	Year of first reactor start up	Year Cancer Registry started	Tumor Registry Data Available on-line				
			County	Years available	Childhood Leukemia	Thyroid cancer	Restriction on # cases (minimum)
AL	1973	1995					
AR	1974	1996	Yes	1997-06	Leukemia (no age grouping)	Yes	5
AZ	1985	1981	Yes	1995-06	Yes (Leukemia x age group)	Yes	None
CA	1962	1988	Yes	1988-06	Leukemia (no age groups)	Yes	15
CO	1953	1979					
CT	1974	1935	Yes	1973-05	Leukemia (no age groups)	Yes	5
FL	1972	1998	Yes	1981-07	Leukemia x age groups	Yes	None
GA	1974	1995	Yes	1999-04	No	No	
IA	1974	1973	Yes	1973-06	Leukemia (no age groups)	Yes	5
IL	1959	1986	Yes	1986-05	Leukemia (no age groups)	No	None
KS	1985	1968	Yes	1997-05	Leukemia (no age groups)	Yes	6
LA	1985	1988					
MA	1963	1982					
MD	1974	1991					
ME	1973	1995					
MI	1963	1985					
MN	1971	1988					
MO	1984	1999	No, only regions	1996-06	Leukemia (choose age group)	No	
MS	1984	1994	Yes	2003-06	Leukemia (no age groups)	Yes	5
NC	1974	1990	Yes	1994-97	Leukemia (no age groups)	Yes	None
NE	1973	1991					
NH	1990	1986					
NJ	1969	1979	Yes	1990-06	Leukemia (no age groups)	Yes	5
NY	1962	1976	Yes	2002-06	Leukemia (no age group)	Yes	None
OH	1947	1992	Yes	2001-05	Leukemia (no age group)	Yes	None
OR	1975	1996					
PA	1961	1990	Yes	1990-06	Leukemia (no age group)	Yes	10 for age-adjusted/ specific rates; 3 for other rates
SC	1970	1995					
SD	1964	1992					
TN	1980	1986					
TX	1988	2000	Yes	1995-06	Leukemia (no age groups)	Yes	16
VA	1972	2001	Yes	1996-04	Yes	Yes	None
VT	1973	1999					
WA	1943	1991	Yes	1992-06	Leukemia (no age groups)	Yes	None
WI	1967	1976					

The availability of cancer incidence data at and below the county level for each state was evaluated using a graded approach based on ease of access to the data. First, websites of states in which NRC-licensed nuclear reactors are located were reviewed for the availability of cancer incidence data. Second, the North American Association of Central Cancer Registries (NAACCR) was contacted. Third, a questionnaire was sent to selected states to collect more specific data concerning the process and cost of accessing tumor registry data.

State Websites

The first effort to determine for the availability of cancer incidence data was a search of the web for cancer incidence data available on-line for each of the states with an NRC-licensed reactor (Table 1). Nineteen of the 35 states of interest have cancer incidence data available on-line. Of these, county data are accessible for 18 states. While many of these states have tumor registries that started before 1990, only five states have data available on-line prior to 1990. Most states typically have data available on their websites from the mid-1990s through 2005.

North American Association of Central Cancer Registries

NAACCR is the national professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care.

NAACCR works in concert with the United States Cancer Statistics (USCS) and the National Program of Cancer Registries (NPCR) to produce the cancer incidence data for the United States. The Centers for Diseases Control (CDC) funds the state tumor registries through the NPCR, and data from the state registries are entered into the USCR. The legislation that established this system was passed in 1992 with the funding of state tumor registries beginning in 1994.

In a phone call on July 9, 2009, the Executive Director of NAACCR indicated that data down to the county level are releasable by NAACCR beginning with 1995 when the NPCR began. NAACCR will only release data from those states that have met the organization's data quality certification, either at the silver or gold level. For years prior to a state achieving one of these levels, NAACCR may release the data after re-reviewing the reason that the state failed to meet the data quality certification. On its website, NAACCR provides the years for which each state achieved certification for the time period 1995-2005. Only 6 of the 35 states interest failed to meet one of these certification levels in that time period: Maryland (4 years), Mississippi (4 years), South Dakota (2 years), Tennessee (4 years), Virginia (4 years), and Wisconsin (7 years) (http://www.cdc.gov/cancer/npcr/uscs/data/00_data_quality.htm accessed October 14, 2009). The Director indicated that data prior to 1995 can be obtained directly from the states, but she did not have any information on the evaluation of the data quality in the state cancer registries prior to 1995.

The following data items needed to carry out a cancer incidence study have been required by NPCR since at least 1997:

- county of diagnosis,
- race,
- sex,

-
- birth date,
 - date of diagnosis,
 - primary cancer site.

Census tract and postal code at diagnosis have also been required elements (NPCR Program Manual, Version 1.0, appendix G, pp 140-144). Although county level, census tract and postal zip code data can be obtained from NAACCR, this organization does not have access to resident address at diagnosis. Therefore, each state must be contacted separately for access to address data.

The Executive Director provided the following information about accessing NAACCR data:

1. To access NAACCR data, one must be a member of NAACCR. The membership application is on-line and the annual fee is \$125.
2. To get permission to use the NAACCR data a proposal must be submitted to the Data Use and Research Committee, which reviews proposals once a quarter to make the determination concerning data release.
3. For approved proposals, data are provided to researchers at no cost.
4. Members can call “town hall meeting” webinars into which other interested members can call. This might be a good vehicle to use to explain the study to those states with NRC-licensed reactors.
5. A priority of NPCR and NAACCR is to make it easier for researchers to get access to cancer incidence data without having to go to each state.
6. NAACCR has a GIS Committee. Each piece of geocoded data has a certainty code associated with it.

In summary, cancer incidence data at the county level from 1995 forward are available from NAACCR at no cost to the researcher with successful application to become a NAACCR member and approval of a research proposal by the NAACCR Data Use and Research Committee. For county data prior to 1995, each state will have to be contacted to obtain the data. The address data can be obtained only from the states. The first year in which resident county and address at diagnosis are available in electronic form from the states is unknown and likely to vary from state to state. Without contacting the states directly, the availability of the data, approval process to access the data, cost, and length of time required to obtain data from the state cancer registries cannot be determined.

Questionnaire response from selected state tumor registries

To obtain more detailed information about the availability of residence address data from each state tumor registry, the original plan was to send each of the 35 states of interest a questionnaire. However, NRC is bound by the Paperwork Reduction Act (PRA) restriction that requires Office of Management and Budget (OMB) clearance of all plans for conducting customer surveys prior to the start of the survey. Under the PRA, customers include state agencies. The PRA allows up to nine customer surveys to be administered without OMB clearance. Consequently, we restricted our questionnaire survey to nine of the 35 states of interest. The states were chosen based on geography and start date of the tumor registry: Arizona, California, Connecticut, Georgia, Illinois, Minnesota, Mississippi, New Jersey, and Tennessee.

The purpose of the questionnaire was to collect information about the state process for approval to access the tumor registry data, the availability of county of residence and resident address at diagnosis, turnaround time and whether or not there is a cost for a data request. The cover letter and questionnaire sent

to the nine states are provided in Appendix A. Table 2 presents the results from the nine states. To summarize the results, IRB approval from a state agency is required to access the data, about half the states charge for the data, and turn-around time on a request is typically less than 3 months. The years for which resident county and address at diagnosis are available in electronic form are the same. However, fewer than half the states queried have this information available electronically since the beginning of the registry. Comparing the first year of reactor start up with the year the registry started, the registry started generally a decade or more after the year of the first reactor start up in the state. Only one state had a registry that predated the first reactor start up in the state. The availability of geocoded resident address data was included in the questionnaire. In each state the time period covered for geocoded address and the address itself was the same, but the software used for geocoding varied considerably across the states.

TABLE 2
State Questionnaire Response Summary

STATE	Year of first reactor start up	Year Registry began	IRB approval?	Other docs?		Charge for data?	County of Residence at Dx?			Residence Address at Dx?		
				Y/N	On-line		Y/N	1st year	Turn-around Time	Y/N	1st year	Turn-around Time
Arizona	1985	1981	Y	Y	N	N	Y	1995	?	Y	1995	?
California	1962	1988	Y	Y	Y	Y	Y	1988	3-4 mo	Y	1988	3-4 mo
Connecticut	1974	1935	Y	Y	N	N	Y	1973	~1 mo	Y	1973	~1 mo
Georgia	1974	1995	Y	N	Y	N	Y	1998	~1 mo	Y	1998	~1 mo
Illinois	1959	1986	Y	Y	N	Y	Y	1986	6-8 mo	Y	1986	6-8 mo
Minnesota	1971	1988	N	Y	N	blank	Y	1988	?	Y	1988	?
Mississippi	1984	1994	N	Y	N	Y	Y	2003	2 mo	Y	2003	2 mo
New Jersey	1969	1979	Y	N	Y	Y	Y	1979	3 mo	Y	1979	2-3 mo
Tennessee	1980	1986	Y	Y	Y	N	Y	2004	2 wks	Y	2004	2 wks

Extrapolating the results from the nine states to all 35 states of interest, we expect that the majority of the states will require IRB review plus some additional documentation to obtain approval to access the registry data. The turn-round time on a request for data should be less than three months with at least half the states likely to charge for the data. While all the states should have county of residence and address at diagnosis in electronic form, the registry data will not include the entire time period of reactor operation in the state. For the 81 sites included in the study, the start year for state cancer registry was the same or an earlier year than the startup year of the site for only 14 of the sites. The median number of years between start of site and start of registry was 11 (Table 3). In addition, the first year of electronic data availability in the cancer registry might be more recent than the registry start year, which was the case for four of the nine states that were queried. Therefore, for the 35 states of interest, it is likely that few will have electronic data available to match all years since the nuclear power plants started up.

TABLE 3
Comparison of Nuclear Facility and Cancer Registry Start Years

State	Reactor	Reactor Years		State Cancer Registry		Registry Start Yr- Reactor Start Yr+	Registry 1st yr elec data- Reactor Start Yr+
		Start	End	Start Year	1st year of electronic data*		
AL	BROWNS FERRY	1973	1985	1995		22	
AL	FARLEY	1977		1995		18	
AL	BELLEFONTE			1995			
AR	ARKANSAS	1974		1996		22	
AZ	PALO VERDE	1985		1981	1995	-4	10
CA	HUMBOLDT BAY	1962	1976	1988	1988	26	26
CA	SAN ONOFRE	1967	1992	1988	1988	21	21
CA	RANCHO SECO	1974	1989	1988	1988	14	14
CA	DIABLO CANYON	1984		1988	1988	4	4
CO	FT ST VRAIN	1973	1989	1979		6	
CT	HADDAM NECK	1974	1996	1935	1973	-39	-1
CT	MILLSTONE	1975		1935	1973	-40	-2
FL	TURKEY POINT	1972		1998		26	
FL	ST. LUCIE	1976		1998		22	
FL	CRYSTAL RIVER	1977		1998		21	
FL	LEVY COUNTY			1998			
GA	HATCH	1974		1995	1998	21	24
GA	VOGTLE	1987		1995	1998	8	11
IA	DUANE ARNOLD	1974		1973		-1	
IL	DRESDEN	1959	1978	1986	1986	27	27
IL	QUAD CITIES	1972		1986	1986	14	14
IL	ZION	1973	1997	1986	1986	13	13
IL	LASALLE	1982		1986	1986	4	4
IL	BYRON	1985		1986	1986	1	1
IL	BRAIDWOOD	1987		1986	1986	-1	-1
IL	CLINTON	1987		1986	1986	-1	-1
KS	WOLF CREEK	1985		1968		-17	
LA	RIVER BEND	1985		1988		3	
LA	WATERFORD	1985		1988		3	
MA	YANKEE-ROWE	1963	1991	1982		19	
MA	PILGRIM	1972		1982		10	
MD	CALVERT CLIFFS	1974		1991		17	
ME	MAINE YANKEE	1973	1996	1995		22	
MI	BIG ROCK POINT	1962	1997	1985		23	
MI	FERMI	1963	1972	1985		22	
MI	PALISADES	1972		1985		13	
MI	COOK	1974		1985		11	
MN	MONTICELLO	1971		1988	1988	17	17
MN	PRAIRIE ISLAND	1974		1988	1988	14	14
MO	CALLAWAY	1984		1999		15	
MS	GRAND GULF	1984		1994	2003	10	19
NC	BRUNSWICK	1974		1990		16	
NC	MCGUIRE	1981		1990		9	
NC	HARRIS	1987		1990		3	
NE	FT CALHOUN	1973		1991		18	

(continues)

State	Reactor	Reactor Years		State Cancer Registry		Registry Start Yr- Reactor Start Yr+	Registry 1st yr elec data- Reactor Start Yr+
		Start	End	Start Year	1st year of electronic data*		
NE	COOPER STATION	1974		1991		17	
NH	SEABROOK	1990		1986		-4	
NJ	OYSTER CREEK	1969		1979	1979	10	10
NJ	SALEM	1976		1979	1979	3	3
NJ	HOPE CREEK 1	1986		1979	1979	-7	-7
NY	INDIAN POINT	1962	1974	1976		14	
NY	GINNA	1969		1976		7	
NY	NINE MILE POINT	1969		1976		7	
NY	SHOREHAM	1989	1989	1976		-13	
OH	DAVIS-BESSE	1977		1992		15	
OH	PERRY	1986		1992		6	
OR	TROJAN	1975	1992	1996		21	
PA	SAXTON	1961	1972	1990		29	
PA	PEACH BOTTOM	1966	1974	1990		24	
PA	THREE MILE ISLAND	1974		1990		16	
PA	BEAVER VALLEY	1976		1990		14	
PA	SUSQUEHANNA	1982		1990		8	
PA	LIMERICK	1985		1990		5	
SC	ROBINSON	1970		1995		25	
SC	OCONEE	1973		1995		22	
SC	SUMMER	1982		1995		13	
SC	CATAWBA	1985		1995		10	
SC	WILLIAMS STATES LEE			1995			
SD	PATHFINDER	1964	1967	2005		41	
TN	SEQUOYAH	1980		1986	2004	6	24
TN	WATTS BAR	1996		1986	2004	-10	8
TX	SOUTH TEXAS	1988		2000		12	
TX	COMANCHE PEAK	1990		2000		10	
TX	VICTORIA COUNTY STATION			2000			
VA	SURRY	1972		2001		29	
VA	NORTH ANNA	1978		2001		23	
VT	VERMONT YANKEE	1973		1999		26	
WA	COLUMBIA GENERATING	1984		1991		7	
WI	LACROSSE	1967	1987	1976		9	
WI	POINT BEACH	1970		1976		6	
WI	KEWAUNEE	1973		1976		3	

Summary

The critical issues concerning the feasibility of doing a cancer incidence study are the existence of cancer incidence data, the time period covered by the incidence data, and the existence of resident county and address at diagnosis data in electronic form.

Existence of cancer incidence data

While no national registry of cancer incidence data exists, the data specific to county and census tract of residence at diagnosis are available from NAACR from 1995 onward for most of the states included in this study. County and census tract data that pre-dates 1995 and resident address data for any time period

can only be obtained from the state cancer registries. While only nine of the 35 states of interest in this study had cancer registries by 1984, the cutoff date for the Jablon study (1990), all 35 states had a cancer registry by 2001. By 1990, 18 of the 35 states had a cancer registry, another 10 had started a registry by 1995, and the remaining seven had one by 2001.

Time period covered by cancer incidence data

Since the nuclear facilities began startup in different years, the time when the cancer registries began must be evaluated in relation to the nuclear facility start up. Ideally, the cancer incidence data would be available prior to the start up of the nuclear facility so that a base-line of the cancer incidence in the study and control areas could be established. That is the case for a very limited number of nuclear facilities. The delay of the start of the cancer registry compared to the nuclear facility is an issue primarily for the county analysis because the spatial analysis doesn't begin until 1990. Given the methodology proposed to compare study and control areas, this delay in the start year of the analysis is not an insurmountable issue.

The start year of the county analysis must be delayed until the year the cancer registry began for all except 14 of the 81 sites. For the remainder, the registry started within 10 years of the reactor start year for 25 sites, between 11 and 19 years for 19 sites, and 20 years or more for 23 sites.

The worst case scenario would be to perform no spatial analysis and to base county analysis on only the NPCR data which is available from NAACR. Those data begin in 1995 and are currently available through 2005. Therefore, at least 11 years of cancer incidence data would be available for all sites except those in the six states that have failed NAACR's certification criteria for one or more years in this time period. It is possible that data for these six states might be released by NAACR after its review of why the state data were not certified for the affected years.

Data for Resident County and Address at Diagnosis in Electronic Form

County of residence at diagnosis is available from NAACR in electronic form beginning in 1995 for most of the 35 states. Census tract and zip code are also available from NAACR. County data before 1995 and any data on resident address at diagnosis, regardless of time period, must be obtained from the states. Those states that have the resident county data in electronic form appear to have the resident address at diagnosis in electronic form covering the same time period as the electronic county of residence. However, based on the limited questionnaire results, the first year that the electronic data are available appears to be after the year cancer registry began in about half the states.

DISCUSSION

There is sufficient cancer incidence data available in an electronic form to do a study of the risk of cancer incidence in populations surrounding nuclear facilities. A relatively cost- and time-efficient county

analysis can be carried out using the county of residence at diagnosis from 1995 onward since the data are available through NAACR at no cost. Similarly, if census tract or zip code available from NAACR is a sufficient surrogate for resident address, a spatial analysis from 1995 onward would also be relatively quick and inexpensive.

Including any data prior to 1995 or resident address in the study will require interaction with the state tumor registry. This will increase the time and cost to do the study. Permission must be made to each state to use its data. Based on the nine states surveyed, it is estimated that about half the states will charge for the requested data. The cost is unknown at this time since what each state charges will depend on what data are requested. A relative comparison of the various data sources is given in Table 4. The resource graphic used in the table serves only to compare the relative magnitude of effort and does not correspond to any specific unit of measure.

TABLE 4
Relative Comparison of Approaches

Approach	Data Source Years Available		Resources Needed		Comments
	NAACR	State	NAACR	State	
County	1995 - 2005	Vary	♂	♂♂♂	Allows comparison to county mortality - time period limited by state tumor registry data.
Spatial					
Census Tract	1990 - 2008	1990	♂♂	♂♂♂♂	Intermediate approach - requires additional evaluation
GIS/Address	Vary - 2005	1990	N/A	♂♂♂♂♂	Allows comparison to spatial mortality

Additional evaluation of the adequacy of resident address in the cancer registries is suggested prior to deciding whether to obtain the addresses or to use census tract as a sufficient substitute for resident address in the spatial analysis. In their study of cancer incidence study for 1993-97 in a population around a nuclear materials facility in Pennsylvania, Boice et al. (2003) found that the mailing addresses in the state cancer registry were accurate in placing an individuals in the same municipality where their post office was located only 60% of the time. The accuracy of the mailing address in placing the individual in the correct municipality was dependent on the type of mailing address and ranged from 92% for a city address to 24% for a rural route and 0% for a highway address. Review of the distribution of each type of resident address in the cancer registry will help to determine the time and cost required to obtain address data in terms of the usefulness of this information in the spatial analysis. Based on what Boice found in his study, use of zip codes in spatial analysis is not recommended.

REFERENCES

Boice Jr., J.D., *et al.* "Cancer Incidence in Municipalities Near Two Former Nuclear Materials Processing Facilities in Pennsylvania." *Health Physics*. Vol. 85, No. 6: pp. 678–690. 2003.

Jablon, S., *et al.* "Cancer in Populations Living Near Nuclear Facilities. Volume 1, Report and Summary." NIH Publication No. 90-874. Washington, DC: U.S. Department of Health and Human Services. July 1990.

APPENDIX A

NRC State Form Letter

<Date>

<Name Department of Health Director>

<Title Department of Health Director>

<State Department of Health>

<Address>

<City>, <State> <Zip>

RE: Request for Information from <Name Vital Statistics Director>, <Title Vital Statistics Director>, <State Vital Statistics>, and <Name Cancer Registry Director>, <Title Cancer Registry Director>, <State Cancer Registry>

Dear <Name Department of Health Director>:

Oak Ridge Associated Universities, Center for Epidemiologic Research, has been tasked by the U.S. Nuclear Regulatory Commission (NRC) to investigate cancer in populations living near NRC-licensed nuclear power facilities. This will provide updated information to the 1990 U.S. National Cancer Institute report, "Cancer in Populations Living near Nuclear Facilities." The new study will assess the cancer mortality of populations living near former, current, and potential new NRC-licensed nuclear facilities. In addition, the NRC has asked us to evaluate cancer occurrence in the area surrounding each facility. This will require access to the address of residence.

After investigating the availability of cancer data in the United States, we concluded the state death records and cancer registries are the most consistent and complete sources of the address data required for this research. Your state has been identified as containing current and/or former nuclear power facilities. We are in the process of determining the availability of address data in electronic format in the death and cancer incidence records in your state.

It is our understanding that <*Name Vital Statistics Director*>, <*Title Vital Statistics Director*>, <*State Vital Statistics*>, and <*Name Cancer Registry Director*>, <*Title Cancer Registry Director*>, <*State Cancer Registry*> are the <State> Vital Statistics and Tumor Registry contacts, respectively. Enclosed are one-page questionnaires for mortality and incidence data that we are asking them to complete and return. If they would prefer to complete the questionnaire electronically, verbally over the phone, or if they have any questions, they can contact me by e-mail at **betsy.ellis@orau.org** or by phone at (865) 576-3528. We will contact them by phone if we have not received their completed surveys by Date.

We thank you and your staff for taking the time to provide valuable information for this national project.

Sincerely,

Elizabeth D. Ellis, Ph.D.
Associate Director
Center for Epidemiologic Research

Enclosures (2):

QUESTIONNAIRE FOR DEATH DATA
QUESTIONNAIRE FOR CANCER REGISTRY DATA

cc + Enclosure (to be returned):

<Name Vital Statistics Director>, <Title Vital Statistics Director>, <State Vital Statistics>
Enclosure (To be completed and returned): QUESTIONNAIRE FOR DEATH DATA

<Name Cancer Registry Director>, <Title Cancer Registry Director>,
<State Cancer Registry>

Enclosure (To be completed and returned): QUESTIONNAIRE FOR CANCER REGISTRY
DATA

QUESTIONNAIRE FOR CANCER REGISTRY DATA

1. Name of State and Registry: _____
2. Is approval required from your state Institutional Review Board (IRB) to make data available to researchers conducting cancer studies? ___ Yes ___ No
3. Other than the IRB, are there other documents that must be completed to apply for access to cancer data? ___ Yes ___ No
If yes,
 Are the documents available online? ___ Yes ___ No
 Is there any cost to researchers for obtaining your data? ___ Yes ___ No
4. Is county of residence at diagnosis available in electronic form in your registry? ___ Yes ___ No
If yes,
 What is the first year that complete electronic county data are available? _____
 Please estimate number of months required for researchers to acquire county data from your registry? _____
5. Is residence address at diagnosis available in electronic form in your registry? ___ Yes ___ No
If yes,
 What is the first year that complete electronic address data are available? _____
 Please estimate number of months required for researchers to acquire address data from your registry, after a well-defined process for maintaining confidentiality is submitted? _____
6. Is residence address at death available in electronic form in your registry? ___ Yes ___ No
If yes,
 What is the first year that complete electronic address data are available? _____
 Please estimate number of months required for researchers to acquire address data from your registry, after a well-defined process for maintaining confidentiality is submitted? _____
7. Are the address data geocoded in your registry? ___ Yes ___ No
If yes,
 What is the first year that these data are available? _____
 What software is used to assign geocodes? _____
8. Please list any additional information below.