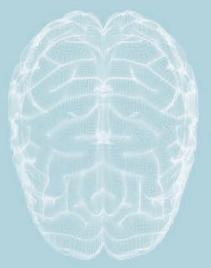


Special Section:

Changes in Surveillance of Brain Cancer in Iowa





2006 CANCER IN IOWA

In 2006, an estimated 6,300 lowans will die from cancer, 14 times the number caused by auto fatalities. Cancer is second only to heart disease as a cause of death. These projections are based upon mortality data the State Health Registry of lowa receives from the lowa Department of Public Health. The Registry has been recording the occurrence of cancer in lowa since 1973, and is one of fourteen population-based registries and three supplementary registries nationwide providing data to the National Cancer Institute. In 2006 an estimated 16,000 cancers will be newly diagnosed among lowa residents. With 2006 Cancer in lowa the Registry makes a general report to the public on the status of cancer. This report will focus on:

- · a description of the Registry and its goals;
- cancer estimates for 2006;
- · a special section on brain and central nervous system tumors;
- brief summaries of recent/ongoing research projects;
- · a selected list of publications from 2005.

THE STATE HEALTH REGISTRY OF IOWA

Cancer is a reportable disease as stated in the Iowa Administrative Code. Cancer data are collected by the State Health Registry of Iowa, located at The University of Iowa in the College of Public Health's Department of Epidemiology. The staff includes more than 50 people. Half of them, situated throughout the state, regularly visit hospitals, clinics, and medical laboratories in Iowa and neighboring states to collect cancer data. A follow-up program tracks more than 99 percent of the cancer survivors diagnosed since 1973. This program provides regular updates for follow-up and survival. The Registry maintains the confidentiality of the patients, physicians, and hospitals providing data.

In 2006 data will be collected on an estimated 16,000 new cancers among lowa residents. In situ cases of bladder cancer are included in the estimates for bladder cancer, to be in agreement with the definition of reportable cases of the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute.

Since 1973 the Iowa Registry has been funded by the SEER Program of the National Cancer Institute. Iowa represents rural and Midwestern populations and provides data included in many NCI publications. Beginning in 1990 about 5-10 percent of the Registry's annual operating budget has been provided by the state of Iowa. Beginning in 2003, the University of Iowa has also been providing cost-sharing funds. The Registry also receives funding through grants and contracts with university, state, and national researchers investigating cancer-related topics.

The goals of the Registry are to:

- · assemble and report measurements of cancer incidence, survival and mortality among lowans;
- provide information on changes over time in the extent of disease at diagnosis, therapy, and patient survival;
- promote and conduct studies designed to identify factors relating to cancer etiology, prevention and control;
- respond to requests from individuals and organizations in the state of lowa for cancer data and analyses;
- provide data and expertise for cancer research activities and educational opportunities.



The State Health Registry of lowa is the best statewide resource for determining the burden of cancer on the lowa population and assessing trends in the occurrence of cancer over time.

CANCER PROJECTIONS FOR 2006

In 2006, cancer will strike five out of every 1,000 lowans. Cancer is the second leading cause of death in lowa, responsible for about 230 of every 1,000 deaths. Breast, colon & rectum, lung, and prostate cancers will account for more than half of all new cancers and cancer deaths.

ESTIMATED NUMBER OF NEW CANCERS IN IOWA FOR 2006

SIOUX 180	5	140N 75		CEOLA 50	DICKINSON 130	EMMET 70		KOSSUTH	NEBAGO 60	4	RTH 5	мітс 7	HELL O	ноw/ 65		WINNESHI 115		4MAKEE 95	5	
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ESTIMATED NUMBER OF CANCER DEATHS IN IOWA FOR 2006

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	FREMONT 15	PAGE 50	TAYLOR 15	RINGG 15		CATUR 20	WAYNE 25	APPAN		20	VAN BUE	REN	LEE 100	V	

New Cancers in Females*

Cancer Deaths in Females

Туре	# of Cancers	% of Total	Туре	# of Cancers	% of Total
Breast	2200	28.2	Lung	740	23.9
Colon & Rectum	1040	13.3	Breast	430	13.9
Lung	950	12.2	Colon & Rectum	330	10.6
Uterus	470	6.0	Pancreas	190	6.1
Non-Hodgkin Lymphoma	320	4.1	Ovary	180	5.8
Skin Melanoma	280	3.6	Non-Hodgkin Lymphoma	140	4.5
Ovary	240	3.1	Leukemia	130	4.2
Thyroid	230	3.0	Uterus	90	2.9
Bladder (invasive and noning	vasive) 220	2.8	Brain	80	2.6
Leukemia	210	2.7	Multiple Myeloma	60	1.9
All Others	1640	21.0	All Others	730	23.6
Total	7800		Total	3100	

^{*}With the exception of bladder, premalignant and nonmalignant tumors are not included in the counts of new cancers provided above.

New Cancers in Males*

Cancer Deaths in Males

Туре	# of Cancers	% of Total	Туре	# of Cancers	% of Total
Prostate	2250	27.5	Lung	1050	32.8
Lung	1250	15.2	Prostate	370	11.6
Colon & Rectum	1000	12.2	Colon & Rectum	330	10.3
Bladder (invasive and noning	nvasive) 560	6.8	Pancreas	170	5.3
Non-Hodgkin Lymphoma	320	3.9	Leukemia	160	5.0
Skin Melanoma	290	3.5	Non-Hodgkin Lymphoma	140	4.4
Kidney & Renal Pelvis	280	3.4	Esophagus	120	3.8
Leukemia	260	3.2	Kidney & Renal Pelvis	100	3.1
Oral Cavity	180	2.2	Bladder	100	3.1
Pancreas	180	2.2	Brain	90	2.8
All Others	1630	19.9	All Others	570	17.8
Total	8200		Total	3200	

^{*}With the exception of bladder, premalignant and nonmalignant tumors are not included in the counts of new cancers provided above.

Fortunately for lowans, the chances of being diagnosed with many types of cancer can be reduced through positive health practices such as smoking cessation, physical exercise, healthful dietary habits, and alcohol consumption in moderation. Early detection through self-examination and regular health checkups can improve cancer survival.

BRAIN AND CENTRAL NERVOUS SYSTEM (CNS) TUMORS

Brain/CNS tumors, whether nonmalignant or malignant, can produce clinical effects that are quite similar in terms of mass effect, swelling, seizure activity, and bleeding. Doctors treating patients with these tumors and researchers studying these tumors feel it is just as important to study nonmalignant brain/CNS tumors as it is to study malignant ones. To address these issues, the National Coordinating Council for Cancer Surveillance (NCCCS) established the Brain Tumor Working Group (BTWG) in January 1997 to review the status of brain tumor surveillance in the United Sates and examine the feasibility of collecting data for nonmalignant brain tumors. Their summary report, Surveillance of Primary Intracranial and Central Nervous System Tumors: Recommendations from the Brain Tumor Working Group (September, 1998; www.naaccr. org) called for 1) a standard definition for use in collecting precise data for all primary intracranial and CNS tumors and 2) a standard site and histology definition for tabulating estimates of these tumors to allow comparability of information across registries. The Council accepted these two recommendations. The standard definition for use was stated as including a primary tumor (whether malignant or nonmalignant) occurring in 1) the brain, meninges, spinal cord, cauda equine, a cranial nerve or nerves. or any other part of the central nervous system; or 2) the pituitary gland, pineal gland, or craniopharyngeal duct.

In 2001, the NCCCS directed the BTWG to provide implementation guidelines to proceed with two more recommendations. The first called for the collection of data for primary intracranial and extracranial CNS tumors by all registries, hospital-based and population-based. This effort necessitated a change in Commission on Cancer (COC) requirements and increased costs to the hospital-based programs and central registry programs. Before additional data collection was

implemented, pilot studies were recommended to assess the procedures and quality control functions needed, as well as the costs of collecting data on these tumors. The second recommendation stated that the appropriate government and professional organizations be involved in carrying out the development and implementation of special training programs and curricula for central registry, hospital registry, and laboratory personnel, as well as the development of computerized edit-checking procedures. Training for reporting and tabulating primary intracranial and CNS tumors was to be offered on a regular basis.

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute conducted pilot studies in New Mexico (1998, 2002), University of Southern California - Los Angeles (1998, 2002), Iowa (2000), and Utah (2002) to evaluate the collection of nonmalignant brain/CNS tumors. SEER funded these special studies to address issues of measuring the extra workload and to determine whether other case finding mechanisms would have to be used. The findings in one study indicated that over one-third of the nonmalignant diagnoses were clinically confirmed (that is, there was only a radiographic diagnosis.) Some studies concluded that there was approximately the same number of nonmalignant tumors as malignant ones. If surveillance was limited to pathologically confirmed tumors, the numbers of nonmalignant and malignant were similar, but if there was an effort to collect the clinically confirmed tumors as well, there were more nonmalignant tumors than malignant. In the end, the recommendation was to collect both clinically and pathologically confirmed tumors.

The North American Brain Tumor Coalition along with members of the brain tumor advocacy community mounted a grassroots campaign to establish federal legislation mandating the col-



lection of nonmalignant brain and CNS tumors. On October 10, 2002, the U.S. Senate and U.S. House of Representatives unanimously passed The Benign Brain Tumor Cancer Registries Amendment Act. After being signed by President Bush, this Act became Public Law 107-260 and required the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries to collect all primary nonmalignant brain, intracranial and CNS tumors. The COC and the SEER Program also began the collection of nonmalignant brain tumors for cases diagnosed on or after January 1, 2004, resulting in 100% participation by U.S. registries.

In order to collect nonmalignant tumors of the brain and CNS at the State Health Registry of lowa, changes had to be made in the lowa Administrative Code. Changes were drafted, including more specific language regarding the Health Insurance Portability and Accountability Act (HIPAA), establishing the State Health Registry of lowa as a public health authority; and changing the definition of reportable cancer to reflect the overall definition of SEER. The changes were adopted by the State Board of Health at their May 11, 2005 meeting and were effective July 13, 2005. Surveillance for nonmalignant brain and CNS tumors began in lowa thereafter.

Findings from the Iowa Pilot Study

The lowa study targeted clinically and pathologically confirmed nonmalignant (benign/uncertain) behavior brain tumors diagnosed in 2000 that conformed to specific site and morphology codes. Based on the lowa experience between 1990 and 1996, it was estimated that 210 newly diagnosed malignant brain/CNS tumors would be reported during the year 2000. Based on the experience of other registries, the number of nonmalignant brain/CNS tumors was estimated to be the same. The Registry identified 213 malignant tumors and 274 nonmalignant brain/CNS tumors in 2000. The breakdown by age and gender is given in Table 1.

TABLE 1. DISTRIBUTION OF PRIMARY BRAIN/CNS TUMORS DIAGNOSED IN 2000 BY AGE GROUP, GENDER AND BEHAVIOR, IOWA

		Brain/CNS Tumor Behavior									
Age in years	Gender	Nonma %	lignant #	Malig %	gnant #	Total % #					
<20 (children)	Male	1.1	3	10.3	22	5.2	25				
	Female	3.3	9	8.0	17	5.3	26				
20-64 (younger adults)	Male	21.2	58	28.6	61	24.4	119				
	Female	24.8	68	20.2	43	22.8	111				
65+ (older adults)	Male	18.2	50	16.0	34	17.2	84				
	Female	31.4	86	16.9	36	25.1	122				
All ages	Male	40.5	111	54.9	117	46.8	228				
	Female	59.5	163	45.1	96	53.2	259				

The female-to-male ratio of nonmalignant tumors was 1.5 to 1.0 whereas for malignant tumors it was 0.8 to 1.0. Among the nonmalignant tumors, 4% were found in children, 46% in younger adults, and 50% in older adults. Among malignant tumors, 18% were found in children, 49% in younger adults, and 33% in older adults. Malignant tumors compared with nonmalignant tumors more commonly occur in children.

The most common site for nonmalignant brain tumors was the meninges (36%) followed by neuro-endocrine and related structures (23%), brain (21%), and spinal cord, cranial nerves & other CNS (20%). The three most common subsite locations were the cerebral meninges (28%), pituitary gland (21%), and acoustic nerve (15%). For malignant brain tumors, the overwhelmingly common site was the brain (91%). The most common specific subsites of the brain were frontal lobe (16%), temporal lobe (16%), overlapping lesion of brain (15%), parietal lobe (9%), and cerebellum (8%).

The most common morphology code assigned nonmalignant brain/CNS tumors was meningioma (46%) followed by pituitary adenoma (20%) and schwannoma (20%). Glioblastoma (38%) was the most common malignant tumor.

Of the 274 nonmalignant tumors, 62% were pathologically confirmed and 38% were clinically confirmed. The clinically confirmed were done so by radiographic procedures. Of the 213 malignant brain tumors, 88% were pathologically confirmed, 8% involved radiography, and 4% involved an unspecified method.

RESEARCH PROJECTS DURING 2006

The State Health Registry of Iowa is participating in over two dozen funded studies during 2006. Brief descriptions of a few of these studies are provided.

The Agricultural Health Study

The Agricultural Health Study is a long-term study of agricultural exposures and chronic disease (especially cancer) among commercial or private pesticide applicators (and their spouses, if married) in Iowa and North Carolina. The study is funded primarily by the National Cancer Institute. We are in the 14th year of the study, which received renewed funding at the end of 2003 for continuation through 2008.

In the first five years, 89,658 subjects (58,564 in lowa and 31,094 in North Carolina) were enrolled in the study. This total for lowa included 31,877 private applicators, 21,771 spouses of private applicators, and 4,916 commercial applicators. Enrollment consisted of completing questionnaires about past exposures and health. The second phase of the study for private applicators and their spouses was completed at the end of 2003. It involved a telephone interview, a mailed dietary questionnaire, and collection of a cheek cell sample from all consenting cohort members. The telephone interview asked about pesticide use since enrollment, current farming and work practices, and health changes. The dietary health questionnaire asks about cooking practices and types of foods eaten. Cooking practices and diet may play a role in cancer and other health conditions. The cheek cells will be used to understand possible links between genetics, exposures, and disease. The second phase of the study was completed with commercial applicators at the end of 2005. The study's third phase began in 2005 and involves updating information about exposures and health.

Since 1997, cohort members have been linked annually to mortality and cancer registry incidence databases in both states. In addition, mortality data on the cohort are being obtained from the National Death Index. More information about recent results from this study, the study background, frequently asked questions, other resources (internet & telephone) for agricultural health information, references for publications to date, and information for scientific collaborators can be found at the website, www.aghealth. org. The abstract and/or full text are available for these publications are provided in the last section of this report.

Lung Cancer Care Outcomes/Surveillance Consortium

This study involves a coordinating center, the State Health Registry of Iowa, and six other primary data collection and research sites across the United States. Across these sites, we are investigating patterns of care for lung cancer, the reasons for particular care decisions by patients and their physicians, variation in dissemination of modern care protocols and practices in different geographic areas, and the effects of these decisions and practices on patient outcomes, including quality of life. We enrolled over 1,000 lowa residents newly diagnosed with lung cancer between June 2003 and March 2005. We are currently working on follow-up interviews and medical record abstraction.

Studies involving Non-Hodgkin Lymphoma (NHL)

The State Health Registry of Iowa with researchers at the Mayo Clinic participated in a collaborative, population-based case-control study of NHL that also involved researchers at the National

Cancer Institute and three other Surveillance, Epidemiology, and End Results (SEER) registries. The main objective of the study was to better characterize risk factors for NHL. In Iowa, 364 live patients newly diagnosed with NHL between July 1, 1998 and June 30, 2000 were enrolled. A similar number of population controls participated. The State Health Registry of Iowa also coordinated the acquisition of pathology reports, slides and tissue blocks from all SEER centers. The slides were reviewed to determine the reliability of NHL pathologic classification. More recently, we are collaborating with researchers at the Mayo Clinic to investigate whether genes with functional, common variant polymorphisms involved in immune function and regulation are associated with overall survival from NHL among these patients. The specific aims are to evaluate: 1) the association of polymorphisms in selected immune-related genes from four key pathways on NHL survival that include genes encoding inflammatory and regulatory cytokines, Th1/Th2 cytokines, innate immunity, and chemokines; 2) whether any effects are independent of other established NHL prognostic factors (such as age and stage) and treatment modalities; and 3) whether any effects are specific to diffuse large B-cell lymphoma or the combination of follicular and small lymphocytic lymphoma. To achieve these aims, medical record reviews were performed to obtain more detailed information on the treatment received for NHL. These research activities resulted in several publications during 2005. The references for these are provided in the last section of this report.

Second Cancer Study of the Gastrointestinal System

The Second Cancer Study of the GI System includes seven case-control investigations with a common primary purpose of evaluating the relation between cancer treatment (radiation and/or chemotherapy) and cancer risk for three gastrointestinal organs (stomach, pancreas, and esophagus). Radiation and chemotherapy are

commonly used as treatment for the first primary cancers in these investigations (Hodgkin disease, cancers of the testis, breast, or cervix). Radiation and chemotherapy may be given with the intention of curing cancer or for cancer control and prolonged life. The cumulative effect may include a risk of developing treatment-induced cancers. The results of this series of studies will help determine if current treatment protocols should be modified to control the risk of second cancers involving the stomach, pancreas, or esophagus. Through 2005, the State Health Registry completed detailed radiation and chemotherapy data collection forms for 90 patients, 30 cases (who had one of the four eligible first cancers followed by one of the three eligible gastrointestinal cancers) and 60 controls (who had one of the four eligible first cancers and none of the eligible gastrointestinal cancers). Over the past two decades the State Health Registry of Iowa has participated in several second cancer studies. These research activities have resulted in several publications. the most recent of which are provided in the references in the last section of this report.

Using Geographic Information to Interpret Cancer Maps

This research is developing and testing a methodology for identifying regions of excess cancer burden for breast and colorectal cancer in lowa. It will refine measures of geographic access to cancer prevention, treatment, and screening services in lowa by computing values using fine-scaled geographic data on individuals, the spatial choices of individuals, and the locations of service providers. It uses State Health Registry of Iowa data for a thirteen-year period and links patient files to Medicare and selected medical insurance records. Statistical models are being computed to associate specific cancer burden measures to predictor variables that capture local characteristics of the area and characteristics of the individuals, while maintaining confidentiality. A regional simulation workbench is being developed to generate the expected range and variations in the cancer burden measures for small geographic areas of lowa based on local demographic characteristics of the area and statewide cancer burden rates. Results can be used to plan more appropriate cancer prevention and control programs.

Geographic Information and Prostate Cancer

This study will focus on reviewing prostate cancer geocoding issues in relation to the geographic information science principle of "fitness for use". This study will ask "for what purposes are prostate cancer incidences geocoded?" and "to achieve each purpose, what are the essential characteristics of the geocoded prostate cancer data?" Our specific aims include producing an edited book of key geocoding issues; preparing "A Primer on Geocoding for Prostate Cancer Prevention and Control Activities"; conducting research and field-testing to compare and evaluate different geocoding methods; and developing methods, and performing experiments on the subject of masking the locations of geocoded prostate cancer incidences sufficient to guarantee their confidentiality, yet leaving them fit for use for many prostate cancer prevention and control purposes.

SEER Patterns of Care Studies

This is a collaborative set of studies between the National Cancer Institute and its 14 SEER Registries. In 2006, we will investigate state-of-the-art therapies for male breast cancer; kidney cancer; node-negative, estrogen receptor positive, female breast cancer; and head and neck cancer. Across these cancer sites, 235 patients will be eligible at the State Health Registry of Iowa and each will have been newly diagnosed during 2004 (male breast cancer involves 2003 as well). The Registry has been involved with these types of studies over the past 20 years. The collected data have resulted in several publications, some of which were published in 2005 and are listed in the last section of this report.

The Iowa Women's Health Study

This is a population-based cohort of 41,837 lowa women, aged 55-69 in 1986, who were recruited to determine whether diet, body fat distribution and other risk factors were related to cancer incidence. Exposure and lifestyle information was collected in a baseline mailed survey and subsequently in several follow-up mailed surveys. Mortality and cancer incidence have been ascertained since 1986 through linkage to the State Health Registry of Iowa databases and the National Death Index. The project has been extremely productive with over 150 publications, some of which occurred in 2005 and are listed in the references provided in the last section of this report. This year Registry staff will begin obtaining pathologic materials for several hundred women in this study who have been diagnosed with colorectal cancer (CRC) as part of a collaborative study with researchers at the Mayo Clinic. The primary aims of the study are to examine associations between environmental factors and CRC subtypes 1) defined by microsatellite instability phenotype, 2) defined by Ki-ras mutation status and p53 mutation status, and 3) defined by gene-specific methylation patterns. The study will be ongoing for the next several years.

Cooperative Agreements and Other Registries

The State Health Registry of Iowa maintains cooperative agreements with several hospital cancer registries and other agencies/entities. Some of the latter include:

- · Iowa Department of Public Health
- Iowa Consortium for Comprehensive Cancer Control
- The University of Iowa
- Center for Health Effects of Environmental Contamination
- Center for Public Health Statistics
- Environmental Health Sciences Research Center
- Health Effectiveness Research Center
- Holden Comprehensive Cancer Center
- Iowa Center for Agricultural Safety and Health
- Injury Prevention Research Center
- Prevention Intervention Center
- Reproductive Molecular Epidemiology Research
 & Education Program

SELECTED 2005 PUBLICATIONS

The Agricultural Health Study

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Non-Hodgkin Lymphoma Case-Control Study

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