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CSTE

Council of State and Territorial Epidemiologists

Epidemiological Capacity of Health Agencies in Cancer Control

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on

Epidemiological Capacity of Health Agencies in Cancer Control and the National Breast and Cervical Cancer Early Detection Program
(NBCCEDP)

October 2000

By

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ACKNOWLEDGMENTS

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In the preliminary phases of the project, meetings were made with DCPC program consultants to become familiar with the cancer activities in the division. Program consultants in the National Breast and Cervical Cancer Early Detection Program assisted by providing information and materials regarding the programs under study. The program consultants for the National Program of Cancer Registries also provided relevant information regarding the cancer activities in the programs.

Following the initiation at the federal level, site visits to selected state health departments were arranged to better understand the organization at the state and local level. Nancy Nowak, RN, MPH, a program consultant with the NBCCEDP, arranged for site visits and provided valuable guidance and advice. State health department staff were very gracious and provided their time, expertise, and assistance in the research process.

Several people from CDC assisted in the design of this study, including Janet Bobo, PhD, Ken Gerlach, MPH, Irene Hall, PhD, and Lisa Richardson, MD, MPH. Members of the ASTCDPD Science & Epidemiology committee, along with CSTE consultants, also provided feedback, including Chris Maylahn, MPH, David Espey, MD, Ursula Bauer, PhD, Richard Hopkins, MD, MSPH, Becky Meriwether, MD, MPH and Phil Huang, MD, MPH.

We would also like to acknowledge Nancy Sonnenfeld, PhD for her help with the pilot process and reviewing the final report.

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EXECUTIVE SUMMARY

BACKGROUND

In 1988, the Institute of Medicine recommended that every health agency "regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems. Health agencies have effectively executed these functions to address infectious disease. However, with the shift to chronic disease as the primary cause of morbidity and mortality, health agencies need to re-direct their efforts to develop epidemiologic capacity to support chronic disease programs.

According to the Public Health Foundation Survey, cancer was the top chronic disease priority in state health agencies. However, many health agencies lack the resources to design, conduct, and analyze epidemiological studies for cancer data. Because epidemiological activities may often be viewed as a lower priority than the immediate requirements associated with delivering public health programs, financial and technical support for these activities may be missing or funded at insufficient levels. This can result in a general lack of infrastructure and capacity for state and local health agencies for cancer epidemiology.

Improved cancer control capacity is expected to translate into more effective chronic disease prevention and control by state and territorial health agencies. The purpose of the study was to determine the needs and capacity of health agencies to use existing epidemiological resources in cancer control activities and to use the information gathered to enhance the agencies' capacity to implement cancer control programs. The Council of State and Territorial Epidemiologists (CSTE) surveyed the state health agencies, the District of Columbia, and several territories to assess the contribution of epidemiology to the efforts of cancer control.

METHODS

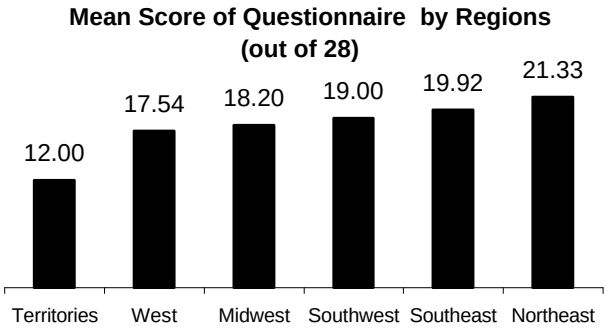
Two survey forms were designed to assess the epidemiological capacity of state and territorial health agencies. The first form was addressed to the chronic disease program director to obtain an overall view of the needs and capacity in cancer control. The second form was to target specific feedback from the Breast and Cervical Cancer Early Detection Program (BCCEDP). Groups of questions focused on cancer control priorities; capacity inputs, including human resources and tools for analysis; and productivity outputs, including use of cancer data for public health practice and dissemination of data.

Data collection began in January, 1999 and was complete in April, 1999. Data were analyzed using Epi-Info and SAS. The frequency of the survey responses were calculated overall and by population. Logistic models were computed comparing the use and dissemination of data with capacity inputs adjusted for population group. Scores were also computed and assigned to each responding state and territory.

CANCER CONTROL RESULTS

Forty-eight of the 54 states and territories surveyed responded, a response rate of 89%. Almost ninety percent (n=43) of the respondents reported having an epidemiologist that devoted some time to cancer control activities. However, the average time an epidemiologist spent on cancer control was under 70%. Fifty-four percent of the epidemiologists had a doctoral degree. Over 50% of the epidemiologists were hired by some type of federal categorical funding. Sixty percent of the respondents had a biostatistician/statistician on staff who spent less than 60% of their time on cancer control activities. Over ninety percent of the epidemiologists had a Pentium-or-equivalent personal computer in their office, with a modem, printer and email capability. Software tools, including those for word-processing, statistics, spreadsheet, database and graphics were available and used by a large percent of the respondents. Over 90% of the respondents reported that the data for mortality, incidence, and risk factor prevalence were available and used in the past year. Only 75% reported that the hospital discharge data was available and less than 50% reported using this data source in the past year. Almost 70% of the respondents produced annual reports. However, less than half reported publishing in a state epidemiology bulletin, professional journal or presenting at a scientific meeting.

Scores were created based on the capacity measures of this questionnaire. Capacity scores ranged from the lowest of 6 to the highest of 27. States' scores varied by region with the East having a higher capacity than the West.

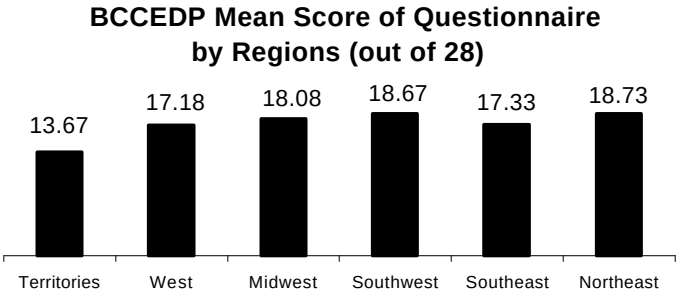


BCCEDP RESULTS

Fifty-two of the 56 states and territories surveyed responded, a response rate of 93%. Seventy-nine percent (n=41) of the respondents reported having an epidemiologist that devoted some time to the BCCEDP. However, the average time an epidemiologist spent on BCCEDP activities was under 60%. Ninety-eight percent of the epidemiologists had a Pentium-or-equivalent personal computer in their office, with a modem, printer and email capability. Software tools, including those for word-processing, statistics, spreadsheet, database and graphics were available and used by a large percent of the respondents. Over 90% of the respondents reported that the data for mortality, incidence,

and risk factor prevalence were available and used in the past year. Less than half reported the availability and use of other survey and surveillance systems. Almost 70% of the respondents produced annual reports. However, very few reported publishing in a state epidemiology bulletin, professional journal or presenting at a scientific meeting

Scores were created based on the capacity measures of this questionnaire. Capacity scores ranged from the lowest of 6 to the highest of 27. States' scores varied by region with the highest scores in the Northeast and Southwest.



CONCLUSION

The results of this survey were promising in terms of human and other resources. Most states and territories responded that they have an epidemiologist and the necessary resources to generate epidemiological information. However, the results demonstrate variability in the capacity to use and disseminate this information.

RECOMMENDATIONS

CSTE is committed to building epidemiologic capacity, through placing epidemiologists in states and territories or providing training to build competency.
CSTE supports the strategic plan for "Developing State-Based Chronic Disease Epidemiology Capacity Nationwide," which has been developed by the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) in collaboration with CSTE and the Association of State and Territorial Chronic Disease Program Directors (ASTCDPD).

Another goal of CSTE is to improve the capacity for state, territorial and local public health agencies to effectively use epidemiologic data to guide public health practice. From the results of this survey, we see that most states reported adequate capacity, however, lack in use and dissemination of the data. A national training agenda could help maximize the existing state capacity. This training could be in collaboration with the many organizations that are conducting capacity and competency assessments.

In terms of increasing capacity through resources and technology, one commitment CSTE can make would be to provide assistance in accessing and linking the necessary

data sets. State hospital data sets are difficult to access in many states. For some, the hospital association has insisted on very limited and difficult access to the dataset. If the dataset is maintained in or by the department of health, access is usually much less of an issue. CSTE could assemble success stories of how state chronic disease or cancer epidemiology programs have been able to obtain access. We could identify key areas that could help a state gain access to and outline the potential uses of this important data set.

Matching or linking the different data sets can provide a broader picture of the target population and help in evaluation of program activities. When the data are linked, not only does this improve obvious deficiencies in the data, but also provides the program with performance characteristics. These measures can be compared with published standards to determine if the program is meeting its goal. Not only morbidity data, but also mortality, insurance, and census data can be used to define the target population and develop intervention strategies for data-based decisions in cancer control. Linking geographical information is becoming key to determining unmet needs in health care. CSTE, again, can provide assistance in training the staff to use the software and matching criteria.

Through position statements or national agenda items, CSTE is committed to increasing the epidemiologic capacity in state and territorial health agencies. Assessments such as these must be followed with immediate action to build capacity in the areas that are shown to be weak and to learn from the areas that are strong. We encourage state and territorial recommendations regarding what CSTE, as an organization, can do to further this process.

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BACKGROUND

In 1988, the Institute of Medicine recommended that every health agency "regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems (IOM, 1988). Health agencies have effectively executed these functions to address infectious disease. However, with the shift of chronic disease as the primary cause of morbidity and mortality, health agencies need to re-direct their efforts toward this trend (Alciati, 1996).

Within the public health system, epidemiology is the link among the system's various parts. Epidemiologists are essential to the efforts of detecting, controlling, and preventing major public health problems. Starting in the 1950s, surveillance and epidemiology programs for infectious disease were established in most state health agencies. A 1975 survey of epidemiologists in state health agencies identified only six states with "noncommunicable disease epidemiologists" (Hinman, 1977)

The practice of noninfectious epidemiology began to increase in the 1980s (Gunn, 1989; Williams, 1988). In 1989, a survey of the southern states identified 12 epidemiologists working specifically in chronic disease (Woernle, 1991). In 1991, Boss et al., completed a survey of 48 state health agencies' staff who practice the epidemiology of noninfectious diseases and conditions (Boss, 1994). This survey identified 49 epidemiologists whose major area of work was a chronic disease or associated behavior.

Although there has been a considerable increase in the number of persons identified as practicing noninfectious disease epidemiology, activity directed at chronic diseases need to be increased in most states health agencies. According to the Public Health Foundation Survey, cancer was the top chronic disease priority in state health agencies (PHF, 1991). This year, it is estimated that 563,100 Americans are expected to die of cancer – more than 1,500 people a day (ACS, 1999). Cancer is the second leading cause of death in the US, 1 of every 4 deaths, exceeded only by heart disease.

Many state and local health agencies lack the resources to design, conduct, and analyze cancer data for epidemiological studies. Because epidemiological activities may often be viewed as a lower priority than the immediate requirements associated with delivering public health programs, financial and technical support may be missing or funded at lower levels. This can result in a general lack of infrastructure and support for state and local health agencies for cancer epidemiology.

To assess the contribution of epidemiology to the efforts of cancer control, the Council of State and Territorial Epidemiologists (CSTE) surveyed the state health agencies, the District of Columbia, and several territories. The purpose of the study was to determine the needs and strengths of health agencies to use existing epidemiological resources in cancer control activities and to use the information for the enhancement of the agencies' capacity to implement cancer control programs. Improved cancer control capacity is expected to translate into more effective disease prevention and control by state and territorial health agencies.

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METHODS

The Council of State and Territorial Epidemiologists (CSTE), in partnership with the Association of State and Territorial Chronic Disease Program Directors (ASTCDPD) and with technical assistance from the Centers for Disease Control and Prevention (CDC) Division of Cancer Prevention and Control (DCPC) implemented this assessment project. An agency's epidemiological capacity is its ability, due to human and other resources, to perform those epidemiological functions necessary to achieve its defined goals and objectives (Brown, 1998). An assessment of epidemiological capacity identifies the specific demonstrated epidemiological abilities of the organization.

In the preliminary phases of the project, meetings were held with DCPC program consultants in the Program Services Branch and the Cancer Surveillance Branch to become familiar with the cancer activities in the division. The program consultants provide technical assistance to and serve as federal liaisons with the state programs. Following the initiation at the federal level, site visits to selected state health departments were arranged to better understand the organization at the state and local level. A workgroup, consisting of DCPC staff, was then established for the assessment process. Members of the ASTCDPD Science & Epidemiology committee, along with CSTE consultants, also provided feedback.

Two survey forms were designed in assessing the epidemiological capacity of state and territorial health agencies. (See Appendix A) The first form was addressed to the chronic disease program director to obtain an overall view of the needs and capacity in cancer control. The second form was to target specific feedback from the Breast and Cervical Cancer Early Detection Program (BCCEDP). Groups of questions focused on: cancer control priorities; capacity inputs, including human resources and tools for analysis; and productivity outputs, including use of cancer data for public health practice and dissemination of data. Because both forms were similar, only form one (the overall form) was pilot tested in four states. These states were chosen from the group of states that currently have an epidemiologist funded by CDC or CSTE. We felt that asking for volunteers from this group, and not from a random sample of the states, would provide us with timely feedback and recommendations. Subsequent to the pilot test, minor modifications were made to the instrument.

CANCER CONTROL SURVEY

In January 1999, surveys were mailed to all voting members of the ASTCDPD. The mail-out included all 50 states, the District of Columbia, Guam, Virgin Islands and America Samoa. The survey included instructions indicating that the form should be completed by the chronic disease program director with assistance from the chronic disease epidemiologist. There was a note indicating that if there was not a person with such a title, the form should be completed by the person responsible for the cancer control activities.

BCCEDP SURVEYS

In January 1999, surveys were mailed to all program directors in the BCCEDP. This included all 50 states, the District of Columbia, Puerto Rico, Virgin Islands, Northern Marianna Islands, Palau, and America Samoa. The survey included instructions indicating that the form should be completed by the BCCEDP Director with assistance from the epidemiologist and/or data manager.

Data collection began in January 1999 and was complete in April 1999 for both forms. Telephone calls were made during this timeframe to those health agencies not yet responding. Once the forms were returned, a summary was mailed back to the states with their responses on each of the two forms. Data were analyzed using Epi-Info and SAS.

The frequency of several capacity inputs and productivity outputs were calculated overall and by population. The population of each state came from 1999 estimates of the U.S. Bureau of the Census (Census, 1999). Population was categorized into two groups for the analysis. Those states or territories falling below the median value of 3,900,000 were categorized into the "Low" population group. All other states were placed in the "High" group, with over 3,900,000 people per state. Because of the small sample size, Fisher's Exact 2-tailed test was constructed to determine a significant difference between the resources among population groups. Logistic models were computed comparing the use and dissemination of data with capacity inputs adjusting for population group. Associations between variables were calculated as odds ratios (OR).

A score was also computed to summarize the frequencies. For example, if the health agency replied with a "yes" to having an epidemiologist devoting some time to cancer then they were given a 1, otherwise the health agency received a 0. The 1's were summed for each health agency and a score was given from 0 to 28 for the entire questionnaire. Scores were computed by section, four sections with 7 YES/NO questions and then summed for an overall questionnaire score, listed below. A one was given to the health agency for each "yes" question addressed below. Questions that were not originally dichotomous in the questionnaire were re-coded to be "yes" or "no". The mean time and years in cancer was computed and states that fell below the mean were coded as "no" or 0. In the section "Use of data", the ways data could be analyzed were summed across the state and the median was calculated based on all respondents. Each state whose sum fell below the median received a 0.

Scores were also computed by demographic variables, such as region and population. The amount of money the program received from CDC was also examined in the BCCEDP surveys.

CANCER CONTROL SURVEY SECTIONS

(TOTAL SCORE 0 TO 28)

Human Resources (score 0 to 7):
At least two epidemiologists involved in analyzing cancer data,
At least 65% of the epidemiologist's time devoted to cancer activities,
At least one Ph.D. level epidemiologist,
Epidemiologist worked in cancer control activities least 7.5 years (average),
At least one epidemiologist staffed with state funds,
A biostatistician/statistician working in cancer
Other staff responding to epidemiologists' needs

Tools (score 0 to 7):
Each epidemiologist has a PC in his or her office
All of the cancer control staff have access to the Internet
Statistical software available
BRFSS available
Cancer registry available
Vital statistics available
Hospital discharge available

Use of data (score 0 to 7):
2000 cancer control objectives
2010 cancer control objectives
Mortality data used in the past year
Morbidity data used in the past year
Risk Factor data used in the past year
Hospital Discharge data used in the past year
Tools to respond to cancer cluster analysis

Dissemination (score 0 to 7):
Produce an annual report
Publish in the State Epi Bulletin
Publish in a Scientific Journal
Attend a cancer conference
Present at a cancer conference
Write a grant
Request to a State Health Official

BCCEDP SURVEY SECTIONS

(TOTAL SCORE 0 TO 28)

Human Resources (score 0 to 7):
An epidemiologist involved in analyzing breast and cervical cancer data
At least 60% of the epidemiologist's time devoted to cancer activities
At least one Ph.D. level epidemiologist
Epidemiologist worked in cancer at least 3.0 years (average),
At least one epidemiologist staffed with state funds
A biostatistician/statistician available to BCCEDP
A data manager available to BCCEDP

Tools (score 0 to 7):
Each epidemiologist has a PC in his or her office
All of the cancer control staff have access to the Internet
Statistical software available
BRFSS available
Cancer registry available
Vital statistics available
Hospital discharge available

Use of data (score 0 to 7):
2000 cancer control objectives
2010 cancer control objectives
MDE data used in the past year
BRFSS used in the past year
Cancer registry used in the past year
Vital statistics used in the past year
Hospital discharge used in the past year

Dissemination (score 0 to 7):
Produce an annual report
Publish in the State Epi Bulletin
Publish in a Scientific Journal
Attend a cancer conference
Present at a cancer conference
Write a grant
Request to a State Health Official

RESULTS

CANCER CONTROL SURVEY

The response rate for the states and the District of Columbia (a denominator of 51) was 90% (n=46), and the response rate for the states, the District of Columbia, and the territories (a denominator of 54) was 89% (n=48). The results include all 48 respondents. (See APPENDIX B for the frequencies of all questions)

Cancer control encompasses all actions taken to reduce the impact of cancer. As a measure of cancer control activities in the health agencies, questions were addressed relative to the priority cancers, risk factors, and control objectives. Thirty-two states currently report on at least five of the cancer sites that are now included in the list of Chronic Disease Indicators reportable nationwide. Tobacco was indicated as the leading priority risk factor, followed by diet and nutrition. Screening and primary prevention were the top cancer control priorities of the health agencies.

In the category of Human Resources, almost ninety percent (n=43) of the respondents reported having an epidemiologist that devoted some time to cancer control activities. However, the time devoted to cancer was not 100%; the average time an epidemiologist spends on cancer control was under 65%. Fifty-four percent of the epidemiologists had a doctoral degree and the average length of time a person had spent working in cancer control was 7.5 years, with a range from less than one year to 30 years. Over 50% of the epidemiologists were hired by some type of federal categorical funding.

Sixty percent of the respondents had a biostatistician/statistician on staff who spent less than 60% of their time on cancer control activities. Over 40% of the statisticians were doctoral level or higher and the average length of time a person had spent working in cancer control was 9.3 years, with a range from less than one year to 22 years. More of the statisticians, compared to the epidemiologists, were hired by state funding (60%).

Twenty-six respondents (54%) had both an epidemiologist and statistician in the health agency working in cancer control. Less than 50% of the states funded other staff who could respond to the epidemiologist's request for assistance (database administrators, systems analysts, or computer programmers).

Almost 90% of the epidemiologists had a Pentium-or-equivalent personal computer in their office, with a modem, printer and email capability. Internet was available to all respondents. Software tools, including those for word-processing, statistics, spreadsheet, database, and graphics were available and used by a large percentage of the respondents.

Previous studies have identified mortality, incidence, risk factor prevalence, and hospital discharge data as the most accessible and potentially useful data sources used to provide a broad picture of the cancer burden (Boss, 1990). Over 90% of the respondents from this study reported that the data for mortality, incidence, and risk factor prevalence was available and had been used in the past year. Only 75% reported the hospital discharge data was available and less than 50% reported using this data source in the past year.

Over 70% of the respondents had published an annual cancer incidence and mortality report. However, less than half reported publishing in a state epidemiology bulletin, professional journal or presenting at a scientific meeting. A greater percentage of epidemiologists did report making contributions to grant applications, requests to State Health Officers, and legislation.

Table 1 was constructed to determine if the capacity inputs differed with population size. Overall the percentages varied among the staffing resources and equipment available. Those states in the high population group had a larger percentage of staffing resources overall. Almost 80% of the states in the high population group reported having an epidemiologist with a doctoral degree working in cancer control. This was much higher than the 43% reported in the low population group. Also, those states in the larger populations had a significantly greater likelihood of having an epidemiologist that is employed with state funds vs. categorical federal funding. None of the Tools and Equipment variables were statistically different among the two population groups.

Table 1. Capacity: Resources that are available to the Health Department for cancer control activities, overall and by population size.

Staffing Resources	***Overall*** **(N=48)** % Yes	***Population^***		***p-value****
		Low % Yes	***High*** % Yes	
Epidemiologist	89.6	84.0	95.6	0.35
With a Doctoral Degree	60.5	42.9	77.3	**0.03**
Over 65% time (FTE) to cancer	64.3	47.6	80.9	0.05
Over 7.5 years worked in cancer	53.8	42.1	65.0	0.21
State funded	47.9	32.0	65.2	**0.04**
Biostatistician	60.4	64.0	56.5	0.77
Database Administrator	53.5	45.5	61.9	0.36
Systems Analyst	34.9	31.8	38.1	0.75
Computer Specialist/Programmer	46.5	21.8	61.9	0.07
Tools and Equipment				
Pentium PC with modem, email & printer	87.5	78.5	96.0	0.09
Internet access to all cancer control staff	81.2	76.0	87.0	0.47
Statistical software available	97.9	96.0	99.9	0.99
Word-processing, spreadsheet & database available	97.9	96.0	99.9	0.99
BRFSS available and used	95.8	99.9	91.3	0.22
State Hospital Discharge Data available and used	41.7	36.0	47.8	0.56
State Cancer Registry available and used	89.6	88.0	91.3	0.90
NHANES available and used	8.3	4.0	13.0	0.34
State Vital Statistics available and used	93.7	99.0	86.9	0.10
SEER available and used	70.8	68.0	73.9	0.76
Current population reports available and used	68.7	56.0	82.6	0.06
Literature searches	75.0	72.0	78.3	0.74

^ Population is divided by the 50th percentile to define Low = 0, 3,900,000 (includes: AK, AR, CT, DC, DE, HI, IA, ID, KS, ME, MS, MT, ND, NE, NH, NI, NM, NV, OK, OR, RI, SC, SD, UT, VT, WV, WY, all territories); High = over 3,900,000 (includes: AL, AZ, CA, CO, FL, GA, IL, IN, KY, LA, MA, MD, MI, MN, MO, NC, NJ, NY, OH, PA, TN, TX, VA, WA, WI)
* P-value derived from Fisher's Exact 2-tailed test to determine a difference between Low and High population percentages.

Table 2 includes the productivity outputs, use of data and dissemination variables. States that fell in the higher population group, again, reported computing these outputs more frequently. Extensive use of morbidity data, including computing incidence rates by several factors and observing trends, was the only variable in the Use of Data section that was significantly different among population groups. However, several variables were significant in the Dissemination section. More respondents in the higher population group produce an annual report, publish in a scientific journal, present at a cancer conference, write a grant, and make requests to a state health official.

Table 2. Productivity/Output: Use and dissemination of cancer control data for public health practice, overall and by population.

Use of Data	***Overall*** **(N=48)** **% Yes**	***Population^***		***p-value****
		Low **% Yes**	***High*** **% Yes**	
2000 cancer control objectives	81.3	84.0	78.3	0.72
2010 cancer control objectives	10.4	8.0	13.0	0.66
Extensive use of mortality data	63.2	53.1	76.0	0.10
Extensive use of morbidity data	59.6	46.9	76.0	**0.03**
Extensive use of risk factor data	54.4	50.0	60.0	0.59
Extensive use of hospital discharge data	15.8	12.5	20.0	0.48
Dissemination				
Produce an annual report	72.9	60.0	87.0	**0.05**
Publish in the State Epidemiology Bulletin	43.7	32.0	56.5	0.14
Publish in a scientific journal	25.0	8.0	43.8	**0.01**
Present at a cancer conference	47.9	24.0	73.9	**0.01**
Write a grant	83.3	68.0	100.0	**0.01**
Request to a state health official	68.8	52.0	87.0	**0.01**
Contribute legislative ideas	62.5	52.0	73.9	0.14
Provide to media	95.8	92.0	100.0	0.49

^ Population is divided by the 50th percentile to define Low = 0, 3,900,000 (includes: AK, AR, CT, DC, DE, HI, IA, ID, KS, ME, MS, MT, ND, NE, NH, NI, NM, NV, OK, OR, RI, SC, SD, UT, VT, WV, WY, all territories); High = over 3,900,000 (includes: AL, AZ, CA, CO, FL, GA, IL, IN, KY, LA, MA, MD, MI, MN, MO, NC, NJ, NY, OH, PA, TN, TX, VA, WA, WI)

* P-value derived from Fisher's Exact 2-tailed test to determine a difference between Low and High population percentages.

Logistic regression models were computed combining the information from Tables 1 and 2. The odds ratios for use of data with several staffing resources are given in Table 3a. Having an epidemiologist with a doctoral degree was associated with an increased use of the priority data sets, with all ratios above one. However, only use of the risk factor data set was significantly associated with this resource. The only other variable that was significant was having a biostatistician available. The OR = 5.54, suggesting that those states or territories with a biostatistician were over 5 times more likely to use their morbidity data to analyze cancer data. Table 3b examines the odds ratios for dissemination outputs with the resources. Again, very few resources were associated with the dissemination outputs.

Table 3a. Odds Ratios for Use of Data Outputs with Resources

Resource	*Use of Data Output*	*% w/ Resource*	*% w/o Resource*	*OR**	*p-value**
Epidemiologist w/ Doctoral Degree	Extensive use of mortality data	84.6	70.6	2.24	0.32
	Extensive use of morbidity data	84.6	64.7	2.76	0.20
	Extensive use of risk factor data	84.6	52.9	9.41	**0.02**
	Extensive use of hospital discharge data	29.6	0	-	-
Epidemiologist w/ over 65% of time devoted to cancer	Extensive use of mortality data	81.4	73.3	1.52	0.61
	Extensive use of morbidity data	81.4	73.3	1.21	0.81
	Extensive use of risk factor data	74.1	66.7	1.86	0.42
	Extensive use of hospital discharge data	22.2	13.3	1.56	0.63
Epidemiologist w/ over 7.5 years worked in cancer	Extensive use of mortality data	71.4	88.9	0.29	0.18
	Extensive use of morbidity data	71.4	88.9	0.23	0.12
	Extensive use of risk factor data	80.7	61.1	3.66	0.10
	Extensive use of hospital discharge data	14.3	22.0	0.53	0.46
State funded epidemiologist	Extensive use of mortality data	78.3	72.0	1.09	0.90
	Extensive use of morbidity data	73.9	68.0	0.91	0.89
	Extensive use of risk factor data	73.9	56.0	2.42	0.18
	Extensive use of hospital discharge data	21.7	16.0	1.33	0.72
Biostatistian available	Extensive use of mortality data	79.3	68.4	1.93	0.34
	Extensive use of morbidity data	82.7	52.6	5.69	**0.02**
	Extensive use of risk factor data	62.1	68.4	0.76	0.66
	Extensive use of hospital discharge data	20.7	15.8	1.44	0.64
Database administrator available	Extensive use of mortality data	82.6	75.0	1.45	0.57
	Extensive use of morbidity data	78.3	75.0	1.02	0.98
	Extensive use of risk factor data	73.9	65.0	1.56	0.47
	Extensive use of hospital discharge data	34.8	00.0	-	-
Systems analyst available	Extensive use of mortality data	93.3	71.4	5.55	0.13
	Extensive use of morbidity data	73.3	78.6	0.69	0.62
	Extensive use of risk factor data	60.0	75.0	0.51	0.32
	Extensive use of hospital discharge data	26.7	14.3	2.11	0.35
Computer specialist available	Extensive use of mortality data	85.0	73.9	1.98	0.40
	Extensive use of morbidity data	80.0	73.9	1.05	0.95
	Extensive use of risk factor data	70.0	69.6	1.14	0.87
	Extensive use of hospital discharge data	25.0	13.0	1.93	0.43

*OR and P-value derived from logistic regression models adjusting for population size
Use of data = Resource ∗ population (categorical; High or low)

Table 3b. Odds Ratios for Dissemination Outputs with Resources

Resource	*Dissemination Output*	*% w/ Resource*	*% w/o Resource*	*OR**	*p-value**
Epidemiologist w/ Doctoral Degree	Produce an annual report	76.9	76.5	0.65	0.59
	Publish in the State Epidemiology Bulletin	53.8	35.3	1.82	0.38
	Publish in a scientific journal	26.9	23.5	0.55	0.49
	Present at a cancer conference	69.2	29.4	3.57	0.09
	Write a grant	100.0	76.5	-	-
Epidemiologist w/ over 65% of time devoted to cancer	Produce an annual report	77.8	80.0	0.47	0.38
	Publish in the State Epidemiology Bulletin	37.4	60.0	0.24	0.07
	Publish in a scientific journal	25.9	20.0	0.71	0.70
	Present at a cancer conference	59.3	40.0	1.12	0.88
	Write a grant	92.6	86.7	0.87	0.90
Epidemiologist w/ over 7.5 years worked in cancer	Produce an annual report	85.7	77.8	1.16	0.87
	Publish in the State Epidemiology Bulletin	42.9	44.4	0.82	0.76
	Publish in a scientific journal	33.3	5.6	6.84	0.10
	Present at a cancer conference	61.9	44.4	1.47	0.60
	Write a grant	100.0	88.9	-	-
State funded epidemiologist	Produce an annual report	82.6	64.0	1.85	0.40
	Publish in the State Epidemiology Bulletin	52.2	36.0	1.47	0.54
	Publish in a scientific journal	39.1	12.0	3.04	0.17
	Present at a cancer conference	65.2	32.0	2.59	0.16
	Write a grant	91.3	76.0	1.64	0.61
Biostatistian available	Produce an annual report	75.9	68.4	1.71	0.44
	Publish in the State Epidemiology Bulletin	48.3	36.8	1.81	0.35
	Publish in a scientific journal	27.6	21.0	1.84	0.43
	Present at a cancer conference	51.7	42.1	2.12	0.29
	Write a grant	79.3	89.5	0.48	0.44
Database administrator available	Produce an annual report	73.9	85.0	0.36	0.22
	Publish in the State Epidemiology Bulletin	47.8	40.0	1.25	0.72
	Publish in a scientific journal	26.1	25.0	0.75	0.71
	Present at a cancer conference	69.6	25.0	7.52	**0.01**
	Write a grant	95.6	80.0	4.54	0.22
Systems analyst available	Produce an annual report	60.0	89.3	0.12	**0.02**
	Publish in the State Epidemiology Bulletin	60.0	35.7	2.65	0.14
	Publish in a scientific journal	46.7	14.3	6.41	**0.03**
	Present at a cancer conference	60.0	42.9	2.03	0.33
	Write a grant	93.3	85.7	2.18	0.41
Computer specialist available	Produce an annual report	75.0	82.6	0.34	0.21
	Publish in the State Epidemiology Bulletin	50.0	39.1	1.32	0.67
	Publish in a scientific journal	30.0	21.7	0.88	0.87
	Present at a cancer conference	55.0	43.5	1.11	0.89
	Write a grant	100.0	78.3	-	-

*OR and P-value derived from logistic regression models adjusting for population size: Dissemination = Resource * population (categorical; High or low)

The data suggest that the states/territories have the necessary resources, both human and other, however lack in the use and dissemination of data. (Chart 1) States' scores varied by region with the East having a higher capacity than the West. (Chart 2) Scores also varied by population size, with an increase trend with a larger population. (Chart 3)

Chart 1. Mean Score by Questionnaire Sections (out of 7)

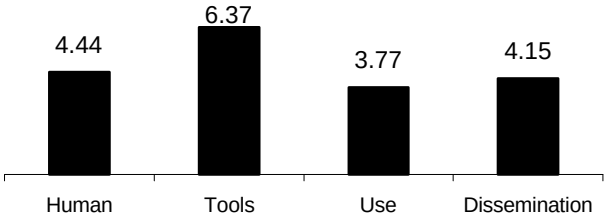


Chart 2. Mean Score of Questionnaire by Regions (out of 28)

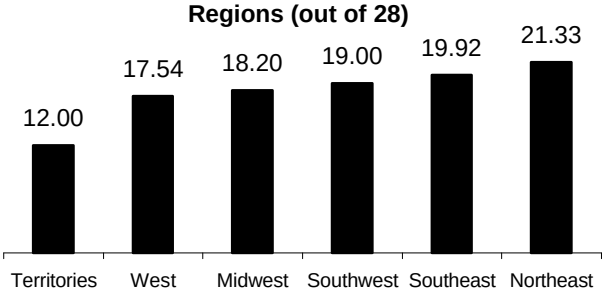
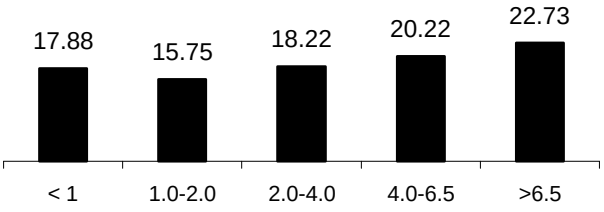


Chart 3. Mean Score of Questionnaire by population (in millions) (out of 28)



BCCEDP SURVEY

The response rate for the states and the District of Columbia (a denominator of 51) was 98% (n=50), and the response rate for the states, the District of Columbia, and the territories (a denominator of 56) was 93% (n=52). The results include all 52 respondents. (See APPENDIX C).

Seventy-nine percent (n=41) of the respondents reported having an epidemiologist that devoted some time to the BCCEDP, with an average time of 60%. Fifty-two percent of the epidemiologists had a doctoral degree. Federal categorical funding was the most common mode of hiring an epidemiologist for the program.

Ninety-eight percent of the epidemiologists had a Pentium-or-equivalent personal computer in their offices, with a modem, printer and email capability. Internet was available to all respondents. Software tools, including those for word-processing, statistics, spreadsheet, database and graphics were available and used by a large percentage of the respondents. However, only 40% indicated that the linkage/matching software was available and only 25% actually used this software.

Over 90% of the respondents reported that the data for mortality, incidence, and risk factor prevalence was available and had been used in the past year. Only 40% reported the hospital discharge data was available and less than 20% reported using this data source in the past year.

In the ways the Minimum Data Elements (MDEs) can be analyzed, a high percentage of programs reported calculating number of women by age and race/ethnicity, percent of abnormal test results, and final diagnosis. However fewer programs reported analyzing the data in ways that may help target specific populations and help in program evaluation, such as calculating trends in screens over time, detection rates by demographic factors, age-adjusted rates, or to compare their data with state-wide or U.S. data.

Almost 70% of the respondents produce annual reports. However, very few reported publishing in a state epidemiology bulletin, professional journal or presenting at a scientific meeting. A greater percentage of epidemiologists did report making contributions to grant applications, requests to State Health Officers, and providing information to the media.

Table 4 was constructed to determine if the capacity inputs for the BCCEDP differed with population size. States in the high population group were much more likely to have the staffing resources and tools for data analysis. However, none of the variables had a statistically significant difference.

Table 4. Capacity: Resources that are available to the Health Department for BCCEDP activities, overall and by population size.

Staffing Resources	***Overall*** (N=52) % Yes	***Population^***		***p-value****
		Low ***% Yes***	***High*** ***% Yes***	
Epidemiologist	78.8	74.1	84.0	0.38
With a Doctoral Degree	46.2	40.7	52.0	0.58
Over 60% time to cancer	42.3	29.6	56.0	0.09
Over 3.0 years worked in cancer	34.6	25.9	44.0	0.25
State funded	17.3	11.1	24.0	0.28
Biostatistican	21.1	25.9	16.0	0.50
Data Manager	88.5	88.9	88.0	0.99
Tools and Equipment				
Pentium PC with modem, email & printer	96.1	96.3	96.0	0.99
Internet access to all cancer control staff	67.3	77.8	56.0	0.14
Statistical software available	94.2	88.9	100.0	0.24
Word-processing, spreadsheet & database available	94.2	92.6	96.0	0.90
BRFSS available and used	92.3	96.3	88.0	0.34
State Hospital Discharge Data available and used	17.3	18.5	16.0	0.99
State Cancer Registry available and used	86.5	85.2	88.0	0.99
NHANES available and used	7.7	7.4	8.0	0.99
State Vital Statistics available and used	84.6	85.2	84.0	0.99
SEER available and used	50.0	48.1	52.0	0.90

^ Population is divided by the 50th percentile to define Low = 0, 3,900,000 (includes: AK, AR, CT, DC, DE, HI, IA, ID, KS, ME, MS, MT, ND, NE, NH, NI, NM, NV, OK, OR, RI, SC, SD, UT, VT, WV, WY, all territories); High = over 3,900,000 (includes: AL, AZ, CA, CO, FL, GA, IL, IN, KY, LA, MA, MD, MI, MN, MO, NC, NJ, NY, OH, PA, TN, TX, VA, WA, WI)

* P-value derived from Fisher's Exact 2-tailed test to determine a difference between Low and High population percentages.

The productivity outputs, use of data and dissemination variables, are included in Table 5. Again, those states with larger populations had a higher percentage of using and disseminating the data as compared to those in the smaller states. Again, none of the variables were statistically different.

Table 5. Productivity/Output: Use and dissemination of BCCEDP data for public health practice, overall and by population.

Use of Data	***Overall*** **(N=52)** % Yes	***Population^***		***p-value****
		Low ***% Yes***	***High*** ***% Yes***	
2000 cancer control objectives	80.8	77.8	84.0	0.73
2010 cancer control objectives	23.1	18.5	28.0	0.52
Extensive use of Minimum Data Elements	61.5	66.7	56.0	0.57
Dissemination				
Produce an annual report	67.3	59.3	76.0	0.24
Publish in the State Epidemiology Bulletin	21.1	18.5	24.0	0.74
Publish in a scientific journal	23.1	22.2	24.0	0.99
Present at a cancer conference	46.1	40.7	52.0	0.58
Write a grant	69.2	63.0	76.0	0.38
Request to a state health official	63.5	59.3	68.0	0.57
Contribute legislative ideas	30.8	22.2	40.0	0.23
Provide to media	80.8	77.8	84.0	0.73

^ Population is divided by the 50th percentile to define Low = 0, 3,900,000 (includes: AK, AR, CT, DC, DE, HI, IA, ID, KS, ME, MS, MT, ND, NE, NH, NI, NM, NV, OK, OR, RI, SC, SD, UT, VT, WV, WY, all territories); High = over 3,900,000 (includes: AL, AZ, CA, CO, FL, GA, IL, IN, KY, LA, MA, MD, MI, MN, MO, NC, NJ, NY, OH, PA, TN, TX, VA, WA, WI)
* P-value derived from Fisher's Exact 2-tailed test to determine a difference between Low and High population percentages.

The data suggest that the states/territories have the necessary tools for analysis, however, as measured by this scoring scheme, lack in human resources. (Chart 4) The use of data for public health practice was the second highest scoring section. Therefore, the programs are using the data, yet lack in disseminating the information. One reason the human resources was not as high as the Cancer Control Survey, is because most epidemiologists' are funded categorically through the BCCEDP and most do not have a biostatistician available. Scores also varied by region, population size, and money awarded to the program, with no obvious trend (Charts 5-7). The highest scores were seen in the Northeast and Southwest as well as the larger states and those with the most money awarded.

Chart 4. BCCDEP Mean Score by Questionnaire Sections (out of 7)

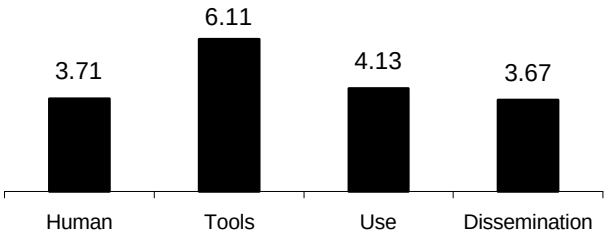


Chart 5. BCCEDP Mean Score of Questionnaire by Regions (out of 28)

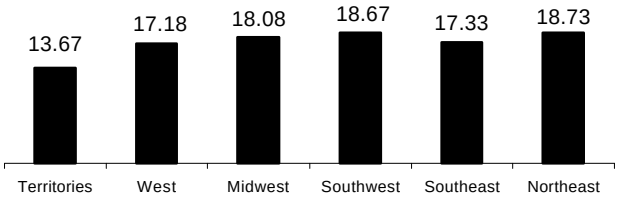


Chart 6. BCCEDP Mean Score of Questionnaire by population (in millions) (out of 28)

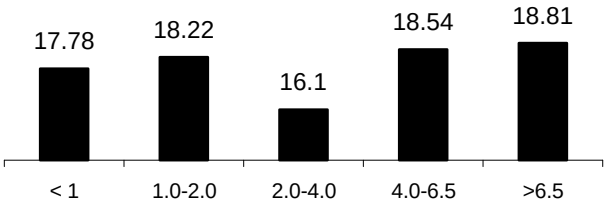
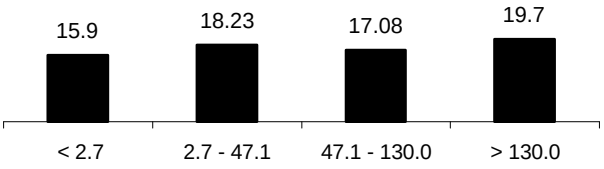


Chart 7. BCCEDP Mean Score of Questionnaire by Money Awarded (in millions) (out of 28)



DISCUSSION

The results of the surveys were promising in terms of human and other resources. Most states responded that they do have at least one epidemiologist and that they do have the necessary resources to generate and use epidemiology information. However, the results demonstrate variability in the states' and territories' capacity to use and disseminate this information for cancer program planning.

The strength of this study is its high response rate. This was facilitated by reminders on the ASTCDPD and Science & Epidemiology conference calls. A main concern of the study is the differences in the way people interpreted and responded to the questions, which could lead to some of the variability. Also, because some of the questions were not directly YES/NO and scores were created, some of the information may not be as evident or straightforward as it might have been using a purely dichotomous questionnaire.

At the Annual Meeting of CSTE in June 1998, with representation from the 50 states and territories, cancer was recommended and adopted as a "reportable disease" as part of the National Public Health Surveillance System. This action was the culmination of a consensus process involving state epidemiologists, public health officials and national organizations to identify and adopt chronic disease indicators for public health surveillance. Cancer mortality (all sites combined), along with incidence and mortality of the lung, breast, cervix, prostate, colon, bladder, melanoma, and oral cavity were adopted as chronic disease indicators in cancer. According to this survey, 32 states (67%) currently report on at least five of these cancer sites as priority cancers in their health department. This indicates an initiative to improve nationwide surveillance of non-infectious conditions.

This study found a difference among the capacity resources and productivity measures by population size. Those in the states that fell in the higher population group were more likely to have the necessary resources and produce the outputs than those located in the lower group. It seems reasonable that those programs in the less populous group would not have the resources, staffing and equipment, because they may not need as many resources as a state with a greater number of people to serve. However, especially for cancer control, there is a notable difference in the dissemination outputs. The programs in the lower group are disseminating the data at a much lower rate. Therefore, these programs may need more resources in order to convey the necessary information in their state or territory.

The dissemination of epidemiological data about cancer is weak in the states and territories surveyed. Ideally health agencies should use reports, bulletin articles, journal columns, presentations and attendance to cancer societies, and press releases for the translation and dissemination of information. Reported usage, however, was low, especially for those vehicles that reach primarily the cancer community—epidemiology bulletins, professional journals and cancer meetings.

The mere presence of a cancer epidemiologist did not predict greater use of these communication channels. In fact, such staffing was associated with very few capacity indicators in the entire survey. Almost all the states had at least one epidemiologist that devoted time to cancer; therefore, the indicator that was used in the Cancer Control analysis to determine the score was two or more epidemiologists.

In conclusion, it seems that the necessary resources and tools are available to the states and territories, however, more emphasis needs to be placed in using and disseminating epidemiologic data. Possible reasons for the lack of use and dissemination of data are that the qualified people who should be doing research are spending time on tasks that are not part of their immediate job descriptions but rather necessary to complete their jobs, such as other managerial tasks.

RECOMMENDATIONS

This survey is a first step in developing a set of norms for public health practice in one specialized area, cancer control. Similar surveys could be done for other specialties of epidemiologic practice. Associations such as the ASTCDPD should consider officially adopting a set of consensus standards and encourage states and territories to measure their own capacity against these standards.

CANCER SURVEYS

In the questionnaire for cancer control, the last section was reserved for comments and suggestions. Respondents were asked to list up to three things that could be included on a "wish list" to build epidemiologic capacity in their state or territory. All responses to this question can be found in a brief report (Appendix D).

The question was addressed in an open-ended fashion. Categories were created to combine common answers, which included Data (data set availability), Funding, Software, Staff, Training, and Other.

Over fifty percent of those that responded to this question requested staff as a wish to build capacity. The common request was for a full-time epidemiologist in cancer control. Other requests for staff were to provide adequate salaries to pay Ph.D. epidemiologists, and to hire statisticians. The second most common request was for the availability of the State hospital discharge data set. Many respondents indicated that there was a problem accessing their hospital discharge data set, perhaps because these data are often managed by agencies other than the health department, such as a state hospital association. Hospital discharge data that is or can be unduplicated is not necessarily even collected in many states, therefore, the issue is not simply access, but collection of the right information. Rapid access to data sets is important if agencies are to respond to legislative requests, make media deadlines and write grant applications on tight timetables.

Overall, the most common request was for an epidemiologist. However, almost 90% of the respondents have an epidemiologist that works in cancer control. Although on average, this person does not spend 100% of their time on cancer control activities and thus, this person may be doing more administrative details than scientific research.

BCCEDP SURVEYS

In the questionnaire for BCCEDP, the last section was also reserved for comments and suggestions. Three questions were addressed to determine what the program participants believe to be the needs, barriers, and wishes to build epidemiologic capacity. Respondents were asked to list up to three of the most important epidemiologic needs, barriers to meeting these needs, and wishes to build epidemiologic capacity in their state or territory. All responses to the questions can be found in a brief report (Appendix E).

The question was open-ended. Categories were later created to combine common answers, which included Analysis/Evaluation, Data/Information, Funding, Software/Equipment, Linkage with cancer registry, Staff/FTEs, Training and Other.

The most common epidemiologic need fell under the category of Analysis/Evaluation. The programs reported that the data needed to be analyzed, both for research and evaluation of the program. Barriers to this need were staff. Respondents commented on not having adequate numbers or trained staff to perform the analysis that needed to be completed. Therefore, the most common wish was for additional staff.

In the Tools category, states were asked if they had available and used the linking/matching software. Only 45% reported that this was available and less than 25% reported that they used this software. After Analysis and Staff, Linking with the registry was the most common request by the programs.

CSTE RECOMMENDATIONS

CSTE is committed to building epidemiologic capacity through placing epidemiologists in states and territories or providing training to build competency.
CSTE supports the strategic plan for "Developing State-Based Chronic Disease Epidemiology Capacity Nationwide," which has been developed by the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) in collaboration with CSTE and the Association of State and Territorial Chronic Disease Program Directors (ASTCDPD). This is the draft position statement that will be addressed at the June 2000 CSTE meeting. Specific objectives and recommendations outlined in the plan include the following:

By 2004, each state health department should be staffed by a state chronic disease epidemiologist. This epidemiologist will work collaboratively with program managers to assure that various epidemiology functions are performed in their state, including:

- coordinating chronic disease surveillance
- providing technical support to program staff and managers
- assessing the adequacy of and gaps in epidemiology capacity.

To the extent possible, state chronic disease epidemiology positions should be created within the state career personnel system at a salary competitive with similar positions in non-state settings. States that face obstacles to creating such a position should consider creating a contract position with a nearby university. A third option is to request a Federal assignee position.

NCCDPHP should provide adequate funding to the Chronic Disease State-based Epidemiology for Public Health Program Support (STEPPS) activity to allow for the recruitment and placement of approximately four state chronic disease epidemiology positions per year from 2000 through 2004 in states that lack one. It is expected that some of these positions will be supported through the CSTE cooperative agreement and some will be federal assignments.

NCCDPHP state awardees should be required to spend some time on epidemiology/surveillance activities. Awardees that lack adequate epidemiology capacity would be required to first use these funds to build this capacity. These funds could be used to support the salary of a state chronic disease epidemiologist.

NCCDPHP should coordinate the development of a "white paper" describing the essential chronic disease epidemiology functions to be performed by states and the capacity required by health departments to perform these functions.

CSTE, ASTCDPD, and NCCDPHP will collaboratively develop an outreach strategy to inform states about the potential benefits of developing chronic disease epidemiology capacity and basic information about the potential funding sources and personnel mechanisms available to support this epidemiology capacity.

CSTE has been named the official agency in charge of coordinating activities related to the Healthy People 2010 objective on epidemiologic capacity of the state health agencies.

HP2010

23-14 *Increase the proportion of Tribal, State and local public health agencies that provide or assure comprehensive epidemiology services to support essential public health services.*

All communities need access to comprehensive epidemiology services so they can quickly detect, investigate, and respond to disease in order to prevent unnecessary transmission. Epidemiologists carry out several essential public health services, including monitoring health status, diagnosing and investigating health problems and health hazards, and conducting evaluation and research.

CSTE has an epidemiologic capacity tool for states to use on a regular basis to monitor capacity changes in their health agencies. Routine self-assessment is important, particularly when the environment of public health is changing. The CSTE Epidemiologic Capacity Assessment guide provides step-by-step procedures for collecting specific information that describes the organization's current epidemiologic capacity to meet its objectives. CSTE is currently working with consultants and members to update the existing assessment tool. CSTE is addressing the charge of Healthy People 2010 by helping states assess their current epidemiologic capacity.

Another goal of CSTE is to improve the capacity for state, territorial, and local public health agencies to effectively use epidemiologic data to guide public health practice. From the results of this survey, we see that most states reported adequate capacity, however, lack in use and dissemination of the data. A national training agenda could help in maximizing the existing state capacity. This training could be in collaboration with the many organizations that are conducting capacity and competency assessments, for example ASTCDPD. CSTE could conduct one- or two- day workshops at the epidemiological regional meetings that are already in place.

In terms of increasing capacity through resources and technology, one commitment CSTE can make would be to provide assistance in accessing and linking the necessary data sets. State hospital data sets are difficult to access in many states. For some, the hospital association has insisted on very limited and difficult access to the data set. If the dataset is maintained in or by the department of health, access is usually much less of an issue. CSTE could assemble success stories of how state chronic disease or cancer epidemiology programs have been able to obtain access. We could identify key areas that could help a state gain access to and outline the potential uses of this important data set.

Matching or linking the different data sets can provide a broader picture of the target population and help in evaluation of program activities. Linking the breast and cervical cancer program data with the cancer registry would give very valuable information to both the BCCEDP and registry. When the data are linked, not only does this improve obvious deficiencies, but also provides the program with performance characteristics of screening mammography and Pap smears. These measures can be compared with published standards to determine if the program is consistent. Not only morbidity data, but also mortality, insurance, and census data can be used to define the target population and develop intervention strategies for data-based decisions in cancer control. Linking geographical information is becoming key to determining unmet needs in health care. CSTE, again, can provide assistance in training the programs to use the software and matching criteria. This training could be conducted at regional meetings or one-or two-day workshops housed at CSTE.

Through position statements or national agenda items, CSTE is committed to increasing the epidemiologic capacity in the state and territorial health agencies. Assessments such as these must be followed with immediate action to build capacity in the areas that are shown to be weak and to learn from the areas that are strong. We encourage state and territorial recommendations regarding what CSTE as an organization can do to further this process.

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APPENDIX A

INCLUDES:

SURVEY FORM FOR CANCER CONTROL

SURVEY FORM FOR NBCCEDP

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A. Cancer Control Priorities

Definition

What is cancer control? (Armstrong, Cancer Causes & Control 3:23-33, 1992)

Cancer control encompasses all actions taken to reduce the impact of cancer. Cancer control may be conceived of in terms of six components which are not mutually exclusive and can be overlapping.

i. *primary prevention*. Actions taken to reduce human exposure to agents that may cause cancer;

ii. *screening*. Actions directed towards asymptomatic people with the objective of identifying those at high risk for cancer for whom some program of continuing screening, diagnosis, and/or therapy may reduce the subsequent morbidity of or mortality from cancer;

iii. *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 cure;

iv. *treatment*. Actions taken in a patient with diagnosed cancer which have cure of the cancer as their objective

v. *rehabilitation*. Actions taken for a cancer patient to restore physical, mental and social function;

vi. *palliative care*. Actions taken in a patient who has cancer that cannot be cured, which have continuing maximization of the patient's physical, mental, and social well-being as their objective.

1. What are the current priority cancers for your state health department?
   List up to five anatomical cancer sites.

   a._____

   b._____

   c._____

   d._____

   e._____

2. What are the current cancer risk factor priorities for your state health department?
   List up to five risk factors.

   a._____

   b._____

   c._____

   d._____

   e._____

3. What are the current cancer control priorities (e.g. see above definition of cancer control) for your state health department? List up to six components.

   a._____

   b._____

   c._____

   d._____

   e._____

   f._____

B. Human Resources in Cancer Control

Definition

Epidemiologist: A scientist who measures the distribution of disease or other health related conditions in defined populations.

1. Does the state employ or contract with an epidemiologist who devotes some time to cancer control?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes, list all that apply.

Last Name	State Employee Report in FTEs	Other (Contracts)* Report in FTEs	Degree/ Field	Years in Cancer Control	Funding source (e.g. state, NPCR, NBCCEDP)
Smith	*0.50*		*PhD/Epi*	*3.5*	*NBCCEDP*

*If unable to report the time in cancer in full time equivalents (FTEs), please give number of hours/time period.

2. Does the state employ or contract with a biostatistician/statistician that the epidemiologist can consult for cancer control activities?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes, list all that apply.

Last Name	State Employee Report in FTEs	Other (Contracts)* Report in FTEs	Degree/ Field	Years in Cancer Control	Funding source (e.g. state, NPCR, NBCCEDP)

*If unable to report the time in cancer in full time equivalents (FTEs), please give number of hours/time period.

3. Does the state fund other staff who can respond to the epidemiologists' request for assistance involved in cancer control activities?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes, report the type of staff involved. Include all staff - professional, support or contract.

Type of Staff	State Employee Report in FTEs	Other (Contracts)* Report in FTEs	Funding source (e.g. state, NPCR, NBCCEDP)
Database Administrators			
Systems Analysts			
Computer Specialist/Programmer			
Certified Tumor Registrar (CTR)			
Other (write-in)			

*If unable to report the time in cancer in full time equivalents (FTEs), please give number of hours/time period.

C. Tools for Analysis in Cancer Control

1. Does each epidemiologist have:

	Yes ✓	No ✓	Some ✓
Pentium-or-equivalent personal computer in his/her office?			
Modem or intranet capability?			
Access to a letter-quality printer?			
Mainframe access?			
Email capability?			

2. Is Internet available?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes,

   a. What proportion of the cancer control staff have access?
      All ⬭ Over Half ⬭ Half ⬭ Less than Half ⬭ None ⬭

3. Indicate, with a check mark, which software tools are *available* for use and which have actually been *used* in the past year for cancer program activities.

Software Tools	*Available* ✓	*Used* ✓
Word-processing (Word, WordPerfect, Other)		
Statistical software (SAS, SPSS, Epi-Info, other)		
Spreadsheet (Excel, Lotus, other)		
Database (Access, FoxPro, Dbase, other)		
Graphics package (PowerPoint, Havard Graphics, other)		
Linkage/Matching software (Automatch, other)		
Query tools (CanQues, HIRS, SEER*Stat, other)		
Other (Specify)		

4. Indicate, with a check mark, which survey and surveillance systems are *available* for use and which have actually been *used* in the past year for cancer program activities.

Survey and Surveillance Systems	*Available* ✓	*Used* ✓
Adult Use of Tobacco Survey		
Behavioral Risk Factor Surveillance System		
State Cancer Registry		
U.S. Census Information		
Current population reports		
Health and Diet Surveys		
Hispanic Health and Nutrition Examination Survey		
State Hospital Discharge Data		
Insurance Information		
Indian Health Services		
Knowledge, Attitudes and Practices Surveys		
Literature searches		
State Medicaid Claims data		
State Medicare Claims data		
Minimum Data Elements (database for NBCCEDP)		
Mortality data		
MCO/Health Plan Administration Database		
National Disease and Therapeutic Index		
National Hospital Discharge Survey		
National Health and Nutritional Examination Survey		
Pathology Laboratory Databases		
SEER		
State Vital Statistics		
Other (Specify)		

D. Use of Cancer Data for Public Health Practice

1. Does the State have a set of cancer control objectives for the year 2000?
   Yes ⬭ No ⬭ Unknown ⬭

2. Does the State have a set of cancer control objectives for the year 2010?
   Yes ⬭ No ⬭ Unknown ⬭

3. Indicate the ways you are using state cancer mortality data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities.

Ways data can be analyzed (by age, race, sex and geographic area)	**Yes ✓**	**No ✓**	**Unknown ✓**
Mortality rates, crude and age-adjusted			
Mapping of mortality rates			
Numbers of deaths by county and region			
Standardized mortality ratios			
Rate ratios of two age-adjusted rates			
Cause-specific years of life lost			
Mortality rate trends			
Projected reductions given proposed goals			
Comparison of county rates to state rate			
Smoking-attributable mortality			
Rank order of state with mortality rates of U.S.			
Rank counties with regard to mortality over time			
Other (specify)			

4. Indicate the ways you are using state cancer morbidity data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities.

Ways data can be analyzed (by age, race, sex and geographic area)	**Yes ✓**	**No ✓**	**Unknown ✓**
Incidence rates, crude and age-adjusted			
Incidence rates by cancer site and sociodemographic variables			
Percent distribution of cancer stage at diagnosis			
Mapping incidence data by county			
Calculation of the probability of developing site-specific cancer			
Annual number of new cases prevented if intervention goals reached			
Treatment provided or not provided			
Survival rates			
Other (specify)			

5. Indicate the ways you are using cancer risk factor data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities.

Ways data can be analyzed (by age, race, sex and geographic area)	**Yes ✓**	**No ✓**	**Unknown ✓**
Prevalence rates of cancer risk factors			
Knowledge about skin cancer			
Knowledge about mammography, Pap test and other screening techniques			
Percent reporting a recent mammogram, Pap test and other screening tests			
Other(specify)			

6. Indicate the ways you are using state hospital discharge data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities.

Ways data can be analyzed (by age, race, sex and geographic area)	**Yes ✓**	**No ✓**	**Unknown ✓**
Rates of hospitalization associated with a diagnosis of cancer			
Inpatient costs associated with cancer care by type of cancer			
Use of hospital resources for cancer patients			
Prevalence of certain types of medical procedures related to cancer care			
Average annual number of hospitalizations			
Analysis of patterns of care among mastectomy patients			
Smoking-attributable health care costs			
Rate of admissions for chemotherapy			
Patient's mean and median length of stay for various cancer sites			
Other (Specify)			

7. Are you using additional data sources to assess the cancer control needs in your state?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes, fill in table with appropriate data set and use of data in planning.

Data Set	**Describe use in cancer control**

8. Do you have the tools to respond to an inquiry about a perceived increased cancer risk? (Cancer Cluster Analysis)

	Yes ✓	No ✓	Unknown ✓
A written protocol			
Identify someone to respond to the inquiry			
Access to cancer incidence and mortality databases for state			
Complete, timely and quality state cancer registry			
Other (write-in)			

E. Dissemination of Data

1. Has the state published an annual cancer incidence and mortality report ?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes, for the most current report indicate the year the data was published _____ and the year of cancer diagnosis or death _____.

2. Has an article on cancer been published by your office in the state's epidemiology bulletin (or similar publication) in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭ Not applicable, no such publication ⬭

3. Has an article on cancer been published by your office in a professional journal in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

4. Did one or more epidemiologists attend a cancer conference in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

5. Did one or more epidemiologists present on a cancer-related topic at a scientific meeting in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

6. Do epidemiologists usually make contributions to the background and needs section of cancer program grant applications?
   Yes ⬭ No ⬭ Unknown ⬭

7. Has the State Health Officer made a special request for information regarding cancer control in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

8. Have epidemiologists had the opportunity to contribute legislative ideas/suggestions related to cancer in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

9. In the past year, have reports on public health problems relating to cancer been provided to the local media by the state health department (e.g. pamphlets, surveys, newspaper)?
   Yes ⬭ No ⬭ Unknown ⬭

10. Does the Health Department have a policy on confidentiality and security of cancer data?
    Yes ⬭ No ⬭ Unknown ⬭

Comments/Suggestions

1. Wish List. What three things are on your wish list to help build epidemiologic capacity in your state cancer control program. (Be specific.)

   a. _____

   b. _____

   c. _____

2. Other. Comments, suggestions, or clarifications of your response.

   _____
   _____
   _____
   _____
   _____
   _____

Please provide the following information about yourself:

Name_____Title_____

State/Territory_____

Agency/Division/Section_____

Phone #_____Email_____

Thank you for your time.

Human Resources in the Breast and Cervical Cancer Program

Definition

Epidemiologist: A scientist who measures the distribution of disease or other health related conditions in defined populations.

1. Does the state employ or contract with an epidemiologist who devotes time to the BCCEDP?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes, list all that apply.

Last Name	State Employee Report in FTEs	Other (Contracts)* Report in FTEs	Degree/ Field	Years in BCCEDP	Funding source (e.g. state, NBCCEDP)
Smith	*0.50*		*PhD/Epi*	*3.5*	*NBCCEDP*

*If unable to report the time in cancer in full time equivalents (FTEs), please give number of hours/time period.

2. Report the type of staff dedicated to the NBCCEDP that correspond with the major activity listed. Report the number of staff in full time equivalents (FTEs).

Major Activities	Epidemiologist	Biostatistican/ statistician	Data Manager	Data Entry	Other (Specify)
Surveillance data management					
Surveillance data analysis					
Coordinate program evaluation activities					
Coordinate program surveillance activities					
Data quality control					
Other (specify)					
Other (specify)					

Tools for Analysis in Cancer Control

1. Does each epidemiologist/data manager have a

	Yes ✓	No ✓	Some ✓
Pentium-or-equivalent personal computer in his/her office?			
Modem or intranet capability?			
Access to a letter-quality printer?			
Mainframe access?			
Email capability?			

2. Is Internet available?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes,
   a. What proportion of the NBCCEDP staff have access?
      All ⬭ Over Half ⬭ Half ⬭ Less than Half ⬭ None ⬭

3. Indicate, with a check mark, which software tools are *available* for use and which have actually been *used* in the past year for cancer program activities.

Software Tools	Available ✓	Used ✓
Word-processing (Word, WordPerfect, Other)		
Statistical software (SAS, SPSS, Epi-Info, other)		
Spreadsheet (Excel, Lotus, other)		
Database (Access, FoxPro, Dbase, other)		
Graphics package (PowerPoint, Havard Graphics, other)		
Linkage/Matching software (Automatch, other)		
Query tools (CanQues, HIRS, SEER*Stat, other)		
Other (specify)		

4. Indicate, with a check mark, which survey and surveillance systems are *available* for use and which have actually been *used* in the past year for cancer program activities.

Survey and Surveillance Systems	*Available* ✓	*Used* ✓
Behavioral Risk Factor Surveillance System		
State Cancer Registry		
Hospital Discharge Data		
Insurance Information		
Minimum Data Elements (NBCCEDP)		
Mortality data		
National Health and Nutrition Examination Survey		
SEER		
State Vital Statistics		
Other (specify)		

Use of Cancer Data for Public Health Practice

1. Does the BCCEDP have a set of cancer control objectives for the year 2000?
   Yes ⬭ No ⬭ Unknown ⬭

2. Does the BCCEDP have a set of cancer control objectives for the year 2010?
   Yes ⬭ No ⬭ Unknown ⬭

3. Indicate the ways you are using the Minimum Data Elements (MDE) database to assess the breast and cervical cancer needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities.

Ways MDE data can be analyzed	Yes ✓	No ✓	Unknown ✓
Number of women enrolled in the program by age group and race/ethnicity			
Percent of women enrolled by county			
Trends in number of first and subsequent screens over time			
Percent of abnormal Pap smears, CBEs and mammograms			
Age-adjusted percent of abnormal Pap smears, CBEs and mammograms			
Percent of abnormal final diagnosis on Pap smears and mammograms			
Cancer detection rates by age-group, race/ethnicity and geographical area			
Percent with a previous Pap smear or mammogram before enrollment			
Percent of abnormal test results with a final diagnosis			
Number of False positives for mammograms and Pap Tests			
Specificity of mammograms and Pap Tests			
Compare MDEs with state-wide and U.S. data			
Link MDEs with cancer registry			
Other (specify)			

Dissemination of Data

1. Does the program produce annual reports?
   Yes ⬭ No ⬭ Unknown ⬭

   If Yes, indicate to whom these reports are made available. Also indicate if these reports are used for evaluation purposes and briefly describe how.

To whom:	**Produce annual reports**		**Use for evaluation**		**Describe**
	Yes ✓	No ✓	Yes ✓	No ✓	
CDC					
Health Department					
State Legislature					
Providers or Contractors					
Other (specify)					

2. Has an article been published on cancer by the program in the state's epidemiology bulletin (or similar publication) in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭ Not applicable, no such publication ⬭

3. Has an article been published on cancer by the program in a professional journal in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

4. Did one or more epidemiologists or data managers from the program attend a cancer conference in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

5. Did one or more epidemiologists or data managers from the program present on a cancer-related topic at a scientific meeting in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

6. Do epidemiologists usually make contributions to the background and needs section of program grant applications?
   Yes ⬭ No ⬭ Unknown ⬭

7. Has the State Health Officer made a special request for information regarding the program in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

8. Have epidemiologists had the opportunity to contribute legislative ideas/suggestions related to the program in the past 12 months?
   Yes ⬭ No ⬭ Unknown ⬭

9. In the past year, have reports on public health problems relating to the program been provided to the local media (e.g. pamphlets, surveys, newspaper)?
   Yes ⬭ No ⬭ Unknown ⬭

10. Does the Health Department have a policy on confidentiality and security of data for the program?
    Yes ⬭ No ⬭ Unknown ⬭

Comments/Suggestions

1. Epidemiologic Needs. What are the three most important epidemiologic needs in your state breast and cervical cancer program?
   a. _____
   b. _____
   c. _____

2. Barriers. What are the barriers to meeting these needs?
   List up to three (be specific).
   a. _____
   b. _____
   c. _____

3. Wish List. What three things are on your wish list to help build epidemiologic capacity in your state breast and cervical cancer program.
   b. _____
   c. _____
   d. _____

4. Other. Comments, suggestions, or clarifications of your response.
   _____
   _____
   _____
   _____
   _____

Please provide the following information about yourself:

Name_____**Title**_____

State/Territory_____

Agency/Division/Section_____

Phone #_____ **Email**_____

Thank you for your time.

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APPENDIX B

INCLUDES:

FREQUENCIES FOR
CANCER CONTROL SURVEY

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N=48 {46 states (RR=90%) & 2 territories (RR=89%)}

A. Cancer Control Priorities

1. What are the current priority cancers for your state health department? **N=47**

Cancer Site	n	%
Breast	47	100
Cervical	44	93.6
Lung	41	87.2
Prostate	22	46.8
Colorectal	33	70.2
Skin	18	38.3
Other	5	10.6
# Cancers listed/state		
2	1	2.1
3	10	21.3
4	7	14.9
5	29	61.7

2. What are the current cancer risk factor priorities for your state health department? **N=46**

Risk factor	n	%
Tobacco	45	97.8
Diet/Nutrition	38	82.6
Physical activity	26	56.5
Sun exposure	14	30.4
Environmental	6	13.0
Screening	18	39.0
Other	23	50.0

3. What are the current cancer control priorities (e.g. see above definition of cancer control) for your state health department? **N=46**

Priorities	n	%
Primary prevention	45	97.8
Screening	46	100
Early diagnosis	32	69.6
Treatment	13	28.3
Rehabilitation	2	4.3
Palliative care	6	13.0
Other	6	13.0

B. Human Resources in Cancer Control

1. Does the state employ or contract with an epidemiologist who devotes some time to cancer control?

Response	**n**		**%**
Yes	43		89.6
No	5		10.4
No. of epi's listed	**n**		**%**
0	5		5.1
1	19		19.4
2	11		11.2
3	5		5.1
4	4		4.1
5	2		2.0
8	2		2.0
Total	98		
			Avg #
Avg. # FTEs State			0.71
Avg. # FTEs Other			0.64
Avg.			0.67
Degree:	**Field**	**n**	**%**
PhD	Epidemiology	15	
	Bio/statistics	2	
	Other	6	
	Missing	8	
	Total	31	31.6
MD	8		8.2
MPH	16		16.3
MS	15		15.3
BS	5		5.1
DVM	2		2.0
PhD/MD	2		2.0
PhD/MPH	7		7.1
MD/MPH	3		3.1
Other	3		3.1
Missing	6		6.1
			Avg. years
Avg. Years in cancer			7.6
Funding Source:			**%**
State	31		33.7
Categorical	48		52.2
Combination	5		5.4
Other	4		4.3
Missing	4		4.3

2. Does the state employ or contract with a biostatistician/statistician that the epidemiologist can consult for cancer control activities?

Response	**n**		**%**
Yes	29		60.4
No	18		37.5
Unknown	1		2.1
No. of statisticans listed	**n**		**%**
0	18		38.3
1	22		46.8
2	2		4.2
3	2		4.2
4	1		2.1
5	1		2.1
6	1		2.1
Unknown	1		2.1
Total			
			Avg #
Avg. # FTEs State			0.58
Avg. # FTEs Other			0.57
Degree:	**Field**	**n**	**%**
PhD	Epidemiology	2	
	Bio/statistics	6	
	Other	4	
	Missing	4	
	Total	16	34.0
MD	1		2.1
MPH	2		4.2
MS	14		29.8
BS	5		10.6
Other	1		2.1
Missing	8		17.0
			Avg. years
Avg. Years in cancer			9.3
Funding Source:			**%**
State	26		55.3
Categorical	13		27.7
Combination	2		4.2
Other	2		4.2
Missing	4		8.5

3. Does the state fund other staff who can respond to the epidemiologists' request for assistance involved in cancer control activities?

Response	n	%
Yes	44	91.7
No	4	8.3

Type of Staff	% Yes
Database Administrators	53.5
Systems Analysts	34.9
Computer Specialist/Program	46.5
Certified Tumor Registrar (CTR)	83.7
Other	37.2

C. Tools for Analysis in Cancer Control

1. Does each epidemiologist have: **n=47**

	Yes %	No %	Some %
Pentium-or-equivalent personal computer in his/her office?	89.4	8.5	2.1
Modem or intranet capability?	91.5	8.5	
Access to a letter-quality printer?	93.6	6.4	
Mainframe access?	50.0	39.1	10.9
Email capability?	91.5	8.5	

2. Is Internet available? **n=48**

Response	%
Yes	100
No	

a. What proportion of the cancer control staff have access? **n=47**

Response	%
All	81.3
Over Half	10.4
Half	0
Less than Half	4.2
None	2.1
Missing	2.1

3. Indicate, with a check mark, which software tools are *available* for use and which have actually been *used* in the past year for cancer program activities. **n=47**

Software Tools	*Available* % Yes	*Used* % Yes
Word-processing (Word, WordPerfect, Other)	100	91.5
Statistical software (SAS, SPSS, Epi-Info, other)	97.9	87.2
Spreadsheet (Excel, Lotus, other)	100	87.2
Database (Access, FoxPro, Dbase, other)	97.9	83
Graphics package (PowerPoint, Havard Graphics, other)	95.7	80.9
Linkage/Matching software (Automatch, other)	51.1	46.8
Query tools (CanQues, HIRS, SEER*Stat, other)	70.2	46.8
Other (Specify)	14.9	14.9

4. Indicate, with a check mark, which survey and surveillance systems are *available* for use and which have actually been *used* in the past year for cancer program activities. **n=47**

Survey and Surveillance Systems	*Available* % Yes	*Used* % Yes
Adult Use of Tobacco Survey	35.4	27.1
Behavioral Risk Factor Surveillance System	100	95.8
State Cancer Registry	97.9	89.6
U.S. Census Information	97.9	85.4
Current population reports	79.2	70.8
Health and Diet Surveys	31.3	25.0
Hispanic Health and Nutrition Examination Survey	16.7	12.5
State Hospital Discharge Data	75.0	41.7
Insurance Information	43.8	35.4
Indian Health Services	20.8	12.5
Knowledge, Attitudes and Practices Surveys	45.8	35.4
Literature searches	83.3	75.0
State Medicaid Claims data	64.6	18.8
State Medicare Claims data	47.9	20.8
Minimum Data Elements (database for NBCCEDP)	89.6	77.1
Mortality data	91.7	89.6
MCO/Health Plan Administration Database	4.2	2.1
National Disease and Therapeutic Index	100	100
National Hospital Discharge Survey	16.7	2.1
National Health and Nutritional Examination Survey	31.3	8.3
Pathology Laboratory Databases	25.0	18.8
SEER	83.3	70.8
State Vital Statistics	100	93.8
Other (Specify)	16.7	16.7

D. Use of Cancer Data for Public Health Practice

1. Does the State have a set of cancer control objectives for the year 2000?

Response	n	%
Yes	39	81.3
No	9	18.8

2. Does the State have a set of cancer control objectives for the year 2010?

Response	n	%
Yes	5	10.4
No	42	87.5
Unknown	1	2.1

3. Indicate the ways you are using state cancer mortality data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities. **n=48**

Ways data can be analyzed (by age, race, sex and geographic area)	**Yes %**	**No %**	**Unknown %**
Mortality rates, crude and age-adjusted	95.8	4.2	
Mapping of mortality rates	47.9	43.8	8.3
Numbers of deaths by county and region	87.5	10.4	2.1
Standardized mortality ratios	56.3	33.3	10.4
Rate ratios of two age-adjusted rates	43.8	45.8	10.4
Cause-specific years of life lost	43.8	54.2	2.1
Mortality rate trends	85.4	8.3	6.3
Projected reductions given proposed goals	25.0	64.6	10.4
Comparison of county rates to state rate	85.4	10.4	4.2
Smoking-attributable mortality	70.8	29.2	
Rank order of state with mortality rates of U.S.	56.3	37.5	6.3
Rank counties with regard to mortality over time	16.7	75.0	8.3
Other (specify)	4.2	95.8	

4. Indicate the ways you are using state cancer morbidity data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities. **n=48**

Ways data can be analyzed (by age, race, sex and geographic area)	Yes %	No %	Unknown %
Incidence rates, crude and age-adjusted	89.6	10.4	
Incidence rates by cancer site and sociodemographic variables	79.2	18.8	2.1
Percent distribution of cancer stage at diagnosis	81.3	12.5	6.3
Mapping incidence data by county	54.2	39.6	6.3
Calculation of the probability of developing site-specific cancer	27.1	62.5	10.4
Annual number of new cases prevented if intervention goals reached	8.3	83.3	8.3
Treatment provided or not provided	18.8	77.1	4.2
Survival rates	33.3	62.5	4.2
Other (specify)	4.2	95.8	

5. Indicate the ways you are using cancer risk factor data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities. **n=48**

Ways data can be analyzed (by age, race, sex and geographic area)	Yes %	No %	Unknown %
Prevalence rates of cancer risk factors	66.7	25.0	8.3
Knowledge about skin cancer	25.0	70.8	4.2
Knowledge about mammography, Pap test and other screening techniques	70.8	25.0	4.2
Percent reporting a recent mammogram, Pap test and other screening tests	93.8	4.2	2.1
Other(specify)	6.3	93.8	

6. Indicate the ways you are using state hospital discharge data to assess the cancer control needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities. **n=48**

Ways data can be analyzed (by age, race, sex and geographic area)	Yes %	No %	Unknown %
Rates of hospitalization associated with a diagnosis of cancer	18.8	75.0	6.3
Inpatient costs associated with cancer care by type of cancer	18.8	72.9	8.3
Use of hospital resources for cancer patients	4.2	85.4	10.4
Prevalence of certain types of medical procedures related to cancer care	10.4	81.3	8.3
Average annual number of hospitalizations	20.8	72.9	6.3
Analysis of patterns of care among mastectomy patients	10.4	81.3	8.3
Smoking-attributable health care costs	33.3	64.6	2.1
Rate of admissions for chemotherapy	2.1	91.7	6.3
Patient's mean and median length of stay for various cancer sites	16.7	77.1	6.3
Other (Specify)	6.3	93.8	

7. Are you using additional data sources to assess the cancer control needs in your state? **n=48**

Response	**%**
Yes	29.2
No	64.6
Unknown	6.3

8. Do you have the tools to respond to an inquiry about a perceived increased cancer risk? (Cancer Cluster Analysis) **n=48**

	Yes %	**No %**	**Unknown %**
A written protocol	54.2	39.6	6.3
Identify someone to respond to the inquiry	89.6	8.3	2.1
Access to cancer incidence and mortality databases for state	93.8	6.3	
Complete, timely and quality state cancer registry	83.3	16.7	
Other (write-in)	2.1	97.9	

E. Dissemination of Data

1. Has the state published an annual cancer incidence and mortality report ?
   If Yes, for the most current report indicate the year the data was published _____ and the year of cancer diagnosis or death _____. **n=48**

Response	%	
Yes	72.9	
No	25.0	
Unknown	2.1	
Year	**Publish %**	**Dx/Death %**
1992		2.9
1995		20.0
1996	8.6	51.4
1997	8.6	20.0
1998	51.4	0
1999	20.0	0
Missing	11.4	5.7

2. Has an article on cancer been published by your office in the state's epidemiology bulletin (or similar publication) in the past 12 months? **n=48**

Response	%
Yes	43.8
No	39.6
N/A	12.5
Unknown	4.2

3. Has an article on cancer been published by your office in a professional journal in the past 12 months? **n=48**

Response	%
Yes	25.0
No	68.8
Unknown	6.3

4. Did one or more epidemiologists attend a cancer conference in the past 12 months? **n=48**

Response	%
Yes	72.9
No	25.0
Unknown	2.1

5. Did one or more epidemiologists present on a cancer-related topic at a scientific meeting in the past 12 months? **n=48**

Response	%
Yes	47.9
No	50.0
Unknown	2.1

6. Do epidemiologists usually make contributions to the background and needs section of cancer program grant applications? **n=48**

Response	%
Yes	83.3
No	16.7

7. Has the State Health Officer made a special request for information regarding cancer control in the past 12 months? **n=48**

Response	%
Yes	68.8
No	29.2
Unknown	2.1

8. Have epidemiologists had the opportunity to contribute legislative ideas/suggestions related to cancer in the past 12 months? **n=48**

Response	%
Yes	62.5
No	33.3
Unknown	4.2

9. In the past year, have reports on public health problems relating to cancer been provided to the local media by the state health department (e.g. pamphlets, surveys, newspaper)? **n=48**

Response	%
Yes	95.8
No	4.2

10. Does the Health Department have a policy on confidentiality and security of cancer data? **n=48**

Response	%
Yes	95.8
No	4.2

APPENDIX C

INCLUDES:

FREQUENCIES FOR THE NBCCEDP SURVEY FORM

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N= 52 { 50 states (RR= 98%) and 2 territories(RR=93%)}

Human Resources in the Breast and Cervical Cancer Program

1. Does the state employ or contract with an epidemiologist who devotes time to the BCCEDP?

Response	**n**		**%**
Yes	41		78.8
No	11		21.2
No. of epi's listed	**n**		**%**
0	11		21.2
1	29		55.8
2	8		15.4
3	2		3.8
4	1		1.9
5	1		1.9
Total	60		
			Avg #
Avg. # FTEs State			0.61
Avg. # FTEs Other			0.62
Degree:	**Field**	**n**	**%**
PhD	Epidemiology	10	
	Bio/statistics	0	
	Other	6	
	Missing	1	
	Total	17	28.3
MD	2		3.3
MPH	15		25.0
MS	7		11.7
BS	3		5.0
DVM	0		0
PhD/MPH	12		20.0
Other	1		1.7
Missing	3		5.0
			Avg. years
Avg. Years in cancer			3.0
Funding Source:	**n**		**%**
State	13		21.7
Categorical	40		66.7
Combination	4		6.7
Other	3		5.0

2. Report the type of staff dedicated to the NBCCEDP that corresponds with the major activity listed. **n=52**

Major Activities	**Epidemiolog** *% Yes*	***Biostatist*** *% Yes*	***Data Mangr*** *% Yes*	***Data Entry*** *% Yes*	***Other*** *% Yes*
Surveillance data management	34.6	11.5	67.3	23.1	9.6
Surveillance data analysis	59.6	19.2	46.2	1.9	7.7
Coordinate program evaluation activities	51.9	1.9	21.2	1.9	42.3
Coordinate program surveillance activities	46.2	3.8	36.5	3.8	17.3
Data quality control	36.5	7.7	71.2	23.1	32.7
Other, specify 27.7	23.1	0	30.8	38.5	23.1
Other, specify 6.4	33.3	0	33.3	0	33.3

Tools for Analysis in Cancer Control

1. Does each epidemiologist/data manager have a **n=52**

	Yes %	**No %**	**Some %**
Pentium-or-equivalent personal computer in his/her office?	98		2
Modem or intranet capability?	98		
Access to a letter-quality printer?	100		
Mainframe access?	51.9	42.3	5.8
Email capability?	98.1		1.9

2. Is Internet available?

RESPONSE	**n**	**%**
Yes	51	98.1
No	0	0
Unknown	0	0
Missing	1	1.9

a. What proportion of the cancer control staff have access?

RESPONSE	n	%
All	35	67.3
Over Half	6	11.5
Half	1	1.9
Less than Half	6	11.5
None	0	0
Missing	4	7.7

3. Indicate, with a check mark, which software tools are *available* for use and which are actually *used* for cancer program activities. **n=52**

Software Tools	*Available* % Yes	*Used* % Yes
Word-processing (Word, WordPerfect, Other)	98.1	96.2
Statistical software (SAS, SPSS, Epi-Info, other)	94.2	88.5
Spreadsheet (Excel, Lotus, other)	96.2	92.3
Database (Access, FoxPro, Dbase, other)	96.2	86.5
Graphics package (PowerPoint, Havard Graphics, other)	98.1	92.3
Linkage/Matching software (Automatch, other)	40.4	25.0
Query tools (CanQues, HIRS, SEER*Stat, other)	36.5	26.9
Other	23.1	23.1

4. Indicate, with a check mark, which survey and surveillance systems are available to be used and which are analyzed for cancer program activities. **n=52**

Survey and Surveillance Systems	*Available* % Yes	*Used* % Yes
Behavioral Risk Factor Surveillance System	98.1	92.3
State Cancer Registry	94.2	86.5
Hospital Discharge Data	67.3	17.3
Insurance Information	51.9	30.8
Minimum Data Elements (NBCCEDP)	98.1	94.2
Mortality data	94.2	88.5
National Health and Nutrition Examination Survey	36.5	7.7
SEER	69.2	50.0
State Vital Statistics	94.2	84.6
Other	17.3	17.3

Use of Cancer Data for Public Health Practice

1. Does the BCCEDP have a set of cancer control objectives for the year 2000?

Response	n	%
Yes	42	80.8
No	7	13.5
Unknown	3	5.8

2. Does the BCCEDP have a set of cancer control objectives for the year 2010?

Response	**n**	**%**
Yes	12	23.1
No	37	71.2
Unknown	3	5.8

3. Indicate the ways you are using the Minimum Data Elements (MDE) database to assess the breast and cervical cancer needs in your state. Mark yes if you have actually *analyzed the data in this way* in the past year for cancer program activities. **n=52**

Ways MDE data can be analyzed	**Yes %**	**No %**	**Unknown %**
Number of women enrolled in the program by age group and race/ethnicity	96.2	3.8	
Percent of women enrolled by county	76.9	21.2	1.9
Trends in number of first and subsequent screens over time	62.7	35.3	2.0
Percent of abnormal Pap smears, CBEs and mammograms	94.1	5.9	
Age-adjusted percent of abnormal Pap smears, CBEs and mammograms	19.6	76.5	3.9
Percent of abnormal final diagnosis on Pap smears and mammograms	82.4	17.6	
Cancer detection rates by age-group, race/ethnicity and geographical area	29.4	66.7	3.9
Percent with a previous Pap smear or mammogram before enrollment	43.1	51.0	5.9
Percent of abnormal test results with a final diagnosis	86.3	13.7	
Number of False positives for mammograms and Pap Tests	25.5	74.5	
Specificity of mammograms and Pap Tests	21.6	78.4	
Compare MDEs with state-wide and U.S. data	62.7	31.4	5.9
Link MDEs with cancer registry	43.1	54.9	2.0
Other (specify)	9.6	88.5	1.9

Dissemination of Data

1. Does the program produce annual reports? **n=52**

Response	n	%
Yes	35	67.3
No	17	32.7

If Yes, indicate to whom these reports are made available. Also indicate if these reports are used for evaluation purposes and briefly describe how.

To whom:	Produce % Yes	Use % Yes
CDC	68.6	60.0
Health Department	68.6	57.1
State Legislature	25.7	20.0
Providers or Contractors	65.7	62.9

2. Has an article been published by the program in the state's epidemiology bulletin in the past 12 months? **n=52**

Response	%
Yes	21.2
No	61.5
N/A	13.5
Unknown	3.8

3. Has an article been published by the program in a professional journal in the past 12 months?

Response	%
Yes	23.1
No	75.0
Unknown	1.9

4. Did one or more epidemiologists or data managers from the program attend a cancer conference in the past 12 months?

Response	%
Yes	76.9
No	23.1

5. Did one or more epidemiologists or data managers from the program present at a scientific meeting in the past 12 months?

Response	%
Yes	46.2
No	53.8

6. Do epidemiologists usually make contributions to the background and needs section of program grant applications?

Response	%
Yes	69.2
No	28.8
Unknown	1.9

7. Has the State Health Officer made a special request for information regarding the program in the past 12 months?

Response	%
Yes	63.5
No	30.8
Unknown	5.8

8. Have epidemiologists had the opportunity to contribute legislative ideas/suggestions related to the program in the past 12 months?

Response	%
Yes	31.4
No	66.7
Unknown	2.0

9. In the past year, have reports on public health problems relating to the program been provided to the local media (e.g. pamphlets, surveys, newspaper)?

Response	%
Yes	80.8
No	15.4
Unknown	3.8

10. Does the Health Department have a policy on confidentiality and security of data for the program?

Response	%
Yes	96.2
No	3.8

APPENDIX D

INCLUDES:

TABLE OF RESPONSE CATEGORIES TO WISH LIST FOR CANCER CONTROL

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Cancer Wish List By Program						
Program	Data	Funding	Software	Staff	Training	Other
Alabama		X		X		
Alaska	X			X		
Arkansas	X			X		X
Colorado				X		
District of Columbia				X		Y
Georgia	X			Y		
Guam		Y		X		
Hawaii			X	X		X
Idaho				Y		
Illinois				X		
Indiana						X
Kansas		X		X	X	
Kentucky				X		
Louisiana				Y		
Maine		X	X	X		
Maryland	X			X		
Massachusetts				Y		
Michigan		X		X		X
Mississippi				X		
Missouri	X			X		X
Montana	X			X		
Nebraska				Y		X
Nevada			X	X		X
New Jersey				Y		X
New Mexico				Y		
New York				Z		
North Carolina				X		
North Dakota				X	Y	
Ohio		X			X	
Oregon	X					
Pennsylvania				X	X	
South Carolina	X		X	X		
South Dakota				X		
Tennessee			X	X		X
Texas	Y					
Utah				X	X	
Vermont				X	X	
Virginia	X			X		
Washington				Z		
West Virginia				X		
Wyoming		Y	X			
Total %	**12%**	**10%**	**7%**	**52%**	**8%**	**12%**

n = 91

X = 1 Response Y = 2 Responses Z = 3 Responses

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APPENDIX E

INCLUDES:

TABLE OF RESPONSE CATEGORIES TO NEEDS, BARRIERS AND WISH LIST FOR BCCEDP SURVEY FORM

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Summary by Program

	Epidemiologic Needs									Barriers									Wish List								
Program	n	Analysis/Evaluation	Data/Information	Equipment/Software	Funds	Linkage	Staff/FTEs	Training	Other	n	Analysis/Evaluation	Data/Information	Equipment/Software	Funds	Linkage	Staff/FTEs	Structure/Communication	Training	Other	n	Analysis/Evaluation	Data/Information	Equipment/Software	Funds	Linkage	Staff/FTEs	Structure/Communication	Training	Other
Alabama	3	Y					X			2						Y				1						X			
Alaska	3	X	X	X						3			X			X	X			1		X							
Arizona	3			X			Y			2						X	X			3						X	X		X
Arkansas	3					X	X		X	2			X	X						1								X	
Colorado	3	Z								3				X		Y				1						X			
Connecticut	2	Y								2						Y				1								X	
District of Columbia	3	Z								3						Y	X			2								X	X
Florida	3	Y				X				2				X					X	2				X		X			
Georgia	2	X		X						2		X				X				1						X			
Hawaii	2		X			X				2			X						X	2						Y			
Illinois	3	Y				X				3				X			Y			3				X		X			X
Indiana	3							X	Y	3						Y	X			3			X			X			X
Kansas	1						X			3			X	X		X				2			X			X			
Kentucky	3		X	X			X			3			X			Y				3		X	X			X			
Louisiana	3		X				Y			2				X		X				3				Y		X			
Maine	2	X				X				1						X				2								X	X
Maryland	3	Y				X				2						X	X			1		X							
Michigan	3	Y				X				3				X		Y				2						Y			
Minnesota	3	Y				X				3				X		X			X	1				X					
Mississippi	3	Z								1						X				1						X			
Missouri	3						Y	X		2				X		X				3				X		X			X
Nevada	3						X		Y	3				X		Y				3		X					Y		
New Jersey	3		X		X			X		3				X		X	X			3			X					X	X
New Mexico	2							X	X	2						Y				3						X		Y	
North Carolina	3		X	X					X	3				X		X	X			3	X		X			X			
North Dakota	3	X		X			X			3			X			Y				2						X		X	
Ohio	3		X		X		X			3				X		X	X			3						Y			X
Republic of Palau	3						Y	X		3	X					Y				2						Y			
Rhode Island	3	Z								3		X		X		X				2		X	X						
South Carolina	3	Z								2			X			X				1									X
South Dakota	1						X			3						X	X		X	2						X	X		
Tennessee	2	X				X				2			X		X					3			X		X			X	
Texas	1						X			1						X				3				X				Y	
Vermont	3						X	X	X	2				X					X	3				X		X			X
Virginia	3						Y	X		3						X			Y	3						Y			X
Washington	2						X		X	3						X	X		X	2								X	X
West Virginia	2						X	X		1						X				1							X		
Wisconsin	3						Z			3				X			X	X		2						Y			
Wyoming	1	X								1				X						1						X			
Total	101	35%	7%	6%	2%	9%	25%	8%	9%	93	1%	2%	9%	18%	1%	45%	14%	1%	9%	81	1%	6%	9%	10%	1%	37%	6%	15%	15%

X = 1 Response Y = 2 Responses Z = 3 Responses