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Using Data to Plan Public Health Programs: Experience From State Cancer Prevention and Control Programs

SYNOPSIS

IN 1989 THE National Cancer Institute funded the second round of Data-Based Intervention Research (DBIR) cooperative agreements with state health agencies to implement a four-phase cancer prevention and control planning model that would establish ongoing cancer prevention and control programs. Activities included identifying and analyzing relevant data to develop a state cancer control plan. The authors reviewed the data analysis and planning activities of five DBIR projects to understand: how states use different types of available data to make public health planning decisions, in what ways available data were sufficient or insufficient for this planning, and the perceived costs and benefits of a data-based planning approach.

Many of the sources of and ways in which health statistics and behavioral data were used were consistent across states. Sources and use of data on the availability and utilization of health services and on cancer control policies were less consistent. Data were most useful in making decisions to address specific cancers, to target populations or regions, to identify general barriers, and to influence policy makers and the public. Data were less influential in identifying specific barriers within target populations and determining what proven intervention components should be implemented and how. The process of pulling this information together and involving working groups and coalitions was considered very beneficial in establishing the credibility of the state health agency in addressing the state's cancer problem. This process relied on a national infrastructure that provided financial resources, sources of data, and research results.

State health agencies are uniquely positioned to address public health needs and have an established tradition of assessing state health problems, establishing policies, and assuring the availability and delivery of services to improve the public health.[1] While health agencies have effectively executed these functions to address infectious diseases throughout much of the twentieth century, more recent trends have required a focus on chronic diseases, in particular cancer. In 1985 the National Cancer Institute (NCI) established specific cancer prevention and control objectives for the nation and identified a critical role for state health agencies in achieving these objectives. As part of this effort, NCI instituted the

Data-based Intervention Research (DBIR) Program with the goal of building the foundation for ongoing cancer prevention and control programs within state health agencies.

To accomplish this goal, each state health department funded under the DBIR Program was to conduct four phases of activity; identifying and analyzing available data (phase I), using these data to develop a state cancer control plan and an implementation plan for high priority intervention areas (phase II), and subsequently implementing (phase III) and evaluating (phase IV) these high priority interventions. Data analysis, planning, and intervention activities focused primarily on the NCI cancer control priority areas of tobacco use reduction, and breast- and cervical-cancer early detection. Many states also addressed diet modification, state-of-the-art treatment, and reduction of environmental and occupational exposures to carcinogens.

While the practice of using health data to guide public health planning efforts is not new, information about how states use available data for comprehensive cancer prevention and control planning is limited. Previous studies have identified what sources of information have been used by state health agencies to assess state cancer problems[2] and have described the process of working with technical working groups and coalitions to identify and analyze data, set priorities, and make program recommendations.[3] Others have provided specific examples of how mortality, incidence, and/or risk factor data can be used to target interventions to high risk groups;[4-6] how knowledge, attitudes and behavior data can be used to determine the focus of interventions;[7-9] and how morbidity and behavioral data can be used to evaluate intervention outcomes.[10,11] Each of these studies provides information about a different component of a comprehensive, data-based planning process for cancer prevention and control.

However, they do not present a clear picture of how these components fit together in a comprehensive state-level planning process, how data are used to establish cancer prevention and control priorities and to identify proven interventions for implementation, and what states perceived to be the costs and benefits of such detailed data-based planning. The purpose of this paper is to describe the results of an analysis of five states' experiences using and integrating available data to develop cancer control plans for their states.

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Methods

For the present analysis, we identified five DBIR states that were roughly comparable on three characteristics. Each state had received funding in Round II of the DBIR Program (1989–1995), each state had completed preparation of a written cancer control plan, and program staff were available for verification of findings. These states included Georgia, Maryland, North Dakota, Vermont, and Washington State.

The first phase of this analysis was a content analysis of program documents leading up to and including the cancer control plan. These documents generally included the original grant proposal, the Year 1 progress report, interim reports, supporting technical documents, and the formal cancer control plan. The authors independently reviewed each set of documents to identify how each state used three categories of data: health data, including mortality and morbidity (incidence); behavioral data, including health behavior, risk factors and determinants of behavior (for example, knowledge, attitudes, beliefs); and environmental and services data, including environmental characteristics such as the presence of cancer control legislation and worksite policies, the availability of early detection equipment to support public health goals in cancer prevention and control, as well as information about the existence of cancer control programs and the utilization of health services. For each type of data, we recorded (a) the specific source of data, (b) the measures used, (c) the type of subgroup analyses performed, and (d) to the extent possible, how the data were used to establish planning priorities and identify interventions. These data were then summarized, as shown in Tables 1–3, to reflect the number of states using each type of data source, data measure, and subgroup analysis as well as the number of states using data to make each type of planning decision identified.

The second phase involved conferences calls with up to three staff members from each study state. In advance of the call staff members received a summary table for their state that combined the observations of both investigators for each type of data. The calls were used to verify and/or correct information. The authors encouraged project leaders to discuss the summary tables with staff members prior to the conference call, particularly staff who might not be available to participate in the call.

Table 1. Health data used for state cancer prevention and control planning

Mortality

| Number of States | Data Sources | Data Analysis | | Use in Planning |
		Measures/Indicators	Analysis By	
4 or 5	Death Certificates	Number of Deaths Age-adjusted Rate Rate Survival (5 years)	Age, Race, Sex Cancer Site Time U.S./Region	Identify magnitude of problem and prioritize among cancer sites.
3	SEER	Leading Causes of Death Percent Change in Rate Smoking-Attributable Deaths	State County/State	
1 or 2	ACS Facts & Figures SAMMEC NCI-EPA CDC/NCHS	Relative Risk Years per Life Lost Smoker/Non-Smoker Ratio Number Smoking-Related Fire Deaths Number Passive Smoke Deaths Percent Deaths Under 60 Years Reduction From Screening Black/White Ratio Out-of-State Deaths		Identify high risk groups and geographic areas. Develop profile of most likely to die. Influence decision-makers.

Morbidity

4 or 5	Regional Registries ACS Facts & Figures	Number/Projected Number Rate	Age, Race, Sex Cancer Site Time	Identify target group by demographic characteristics or region.
3	SEER Literature Hospital Discharge/ Abstract Review	Stage at Diagnosis	Region	
1 or 2	State-based Studies and Surveys	Early/Late Stage Ratio Deaths/Incidence Ratio Black/White Ratio Magnitude of Risk Projected Number Due to Tobacco Discharge Status Percent Captured by Cost Review System	Income	Provide to local region(s) for planning. Combine national estimates and state demographics to educate policy-makers.

Results

Health Data. As reflected in Table 1, state-specific mortality data were used by all states. States generally relied on a small number of measures, such as number of state deaths, age-adjusted death rates for the state, and survival (percent surviving five years). These analyses formed the basis for assessing mortality trends and comparing state mortality rates to the U.S. rate as well as comparing rates across counties or health districts in the state. Mortality data were used to assess the overall magnitude of the cancer problem and to identify specific cancer sites that most contributed to the problem. In one case, mortality data were used to develop a state's cancer profile of "a typical individual" at high risk for dying from cancer.

All study states also presented morbidity data analyzed by various demographic factors and expressed as the num-

ber, or projected number, of new cancer cases (Table 1), with fewer states presenting site-specific incidence rates or stage-at-diagnosis information. All study states expressed concern about the quality and/or coverage of available incidence data. These data were most often used to narrow the scope of interventions, by identifying specific target groups and/or geographic regions with high incidence rates.

Behavioral Data. Table 2 presents information about the use of behavioral data, including knowledge, attitudes, beliefs, and practices. Behavioral data primarily addressed tobacco use and early detection of breast and cervical cancer. The Behavioral Risk Factor Surveillance System (BRFSS) was the primary source of state-specific behavioral data, and most states supplemented this with information from the scientific literature and state-based surveys and studies. Behavioral data were used primarily to identify target

Table 2. Behavioral data used for cancer prevention and control planning

Behavior

| | | Data Analysis | | |
Number of States	Data Sources	Measures/Indicators	Analysis By	Use in Planning

4 or 5	BRFSS
	Tobacco Consumption
	Literature
		Prevalence
		Screening Frequency
		Tobacco Consumption
			Time
			Demographics
			Region
			Vs. U.S., Other
			    States
				Identify target groups for intervention
				    programs.
				Identify lack of need for targeted
				    programs.

3	High School/Youth
	    Surveys
	NHIS
		Percent Births to Smoking Mothers
		Amount Smoked
		Smokeless Tobacco Prevalence
		Diet-related (e.g., Percent Eating
		    Protective Foods, Patterns of
		    Obesity, Alcohol Consumption)		

1 or 2	Birth Certificate
	WIC Program[1]
	SCIP Program[2]
	ACS Provider Survey
	Surveys
	COMMIT
	Provider Survey
	Health Risk Survey
	Abnormal Pap
	    Followup Study
	Cervical Cancer Study
	Breast Cancer Study
	SAMMEC
		Providers' Behavior
		Number Screened Projected
		    to Population
		Tobacco Use Quit Rate
		Percent Cancer Detection by
		    Method
		Percent National Tobacco Consumption
		Percent Breast Self Exam
		Percent Clinical Breast Exam
		Rate of Risk Behaviors
			State
			Medicaid
				Identify what providers are doing.
				Evaluate awareness of issue.
				Prioritize interventions.

Determinants of Behavior

4 or 5	Literature
	BRFSS
	Regional Surveys
		Knowledge of/Attitude
		    About Cancer, Risk
		    Factors, Screening
			Age, Race,
			Education
				Identify barriers to screening.
				Identify providers barriers.

1 or 2		Efficacy of Interventions Magnitude of Risk Barriers to Screening	Time Region	Used local research results to influence change.

[1]Women, Infant, and Children (WIC)
[2]Smoking Cessation in Pregnancy (SCIP)

groups for intervention; information about knowledge, attitudes, and beliefs was used primarily to identify barriers.

Environmental and Health Services Data. As reflected in Table 3, the majority of study states provided at least some information about environmental factors demonstrated to influence cancer control practices, such as state legislation and health services data, such as utilization of hospital and screening services, and the cost of services. The most important sources for this information were hospital discharge datasets and state and local surveys. Unlike the patterns observed for health and behavioral data, the sources, indicators, subanalyses, and volume of information about environmental influences and cancer control services varied considerably across study states.

These data provided information about "what existed" and was used primarily in combination with other data. States differed in how this information was combined with other data and in how they used this information to guide planning. For example, information about the distribution of services across the state and potential differences in utilization were combined with other types of data to assess the relationship between utilization and need. In some cases this analysis focused on assessing the level of service utilization at different physical locations in the state, while in others it focused on service utilization by high risk groups, and many times these factors were highly related.

Another important use of this information was to raise awareness about available services and to combat misconceptions about underutilization of services. For example, in

Table 3. Environmental and services data used for cancer prevention and control planning

Number of States	Data Sources	Data Analysis		Use in Planning
		Measures/Indicators	Analysis By	
Health Services Utilization				
4 or 5	Hospital Discharge Surveys Screening Facility Records	Number Screened Per Year Hospitalizations Hospital Costs Payment/Medicaid Percent Uninsured		
3	Department of Health American Cancer Society Literature	Cost of Smoking	Region	Identify where services are being used. Assess whether service utilization matches need. Raise awareness.
1 or 2	Chart Reporting Hospital Abstract Reporting Payment Records SAMMEC National Data Estimates NCI (PDQ use) Local/Health Service Experts	Frequency of Health Visits Use of State Clinics Use of PDQ Lifetime Earnings Lost Cost Savings of Intervention Cost of PAP/Life Saved Number/Procedures Percent Procedures	Demographics Type Time	Assess potential underutilization. Assess quality. Magnitude of problem.
Environmental Supports & Deterrents				
4 or 5	Department of Health Relevant State Agency Legislation Regional Surveys Literature	Number Mammography Units Sample Screening Costs Legislative Provisions Quality Assurance		
3	Reimbursement			Identify enabler legislation for tobacco control & early detection.
1 or 2	State Regulatory Office Medicaid State Board of Medical Examiners Directory of Medical Specialists ACOS-approved Facilities[1] ACR Mammography Units[2] Federal Code Local Officials/Meetings	Relationship Between Smoking Policies & Cessation Knowledge/Attitudes About Tobacco Laws/Ordinances Worksites With Tobacco Policies Use of Y2000 Tobacco Curricula Screening Capacity Excise Taxes Radon Levels	Restaurant Type	Identify barriers to service access. Provide record of action.
Existing Programs				
4 or 5	Department of Health Relevant State Agency Legislation Regional Surveys Literature	Number of Mammography Units Sample Screening Costs Legislative Provisions Quality Assurance		Identify areas without service and/or weak components of existing services.
3	ACOG-approved Facilities Literature		Region	
1 or 2	Cancer Information Service State Board of Medical Examiners Medicaid Physician Survey Director of Medical Specialists Inventory of Programs	NCI Program Meetings Organization of Programs/Services Program History	Race	Build on existing programs. Identify networking needs. Identify readiness to change. Availability, feasibility, effectiveness of intervention programs.

[1]American College of Surgeons (ACOS)
[2]American College of Radiology (ACR)

Vermont, many were advocating for purchase and promotion of mobile mammography vans as an approach to increasing breast cancer early detection. Analysis of health services utilization data, however, revealed underutilization of existing mammography units and access within 30 miles for every woman in the state.

While states in this study may have differed in the relative emphasis placed on each of these planning issues, study states generally agreed that information about the environment provided a sense of how much attention was being placed on cancer control issues within key intervention channels in their state and provided direction through identification of ready partners and strategies.

Discussion

This analysis of five states' experiences in using available data to develop comprehensive state cancer control plans indicates that these states identified and used a broad range of health, behavioral, and environmental and services data to characterize the cancer problem in their states. Many of the health and behavioral data sources, data limitations, measures and analyses as well as the ways in which these data were used for public health planning were consistent across states. Morbidity was characterized primarily by disease incidence, and none of the five states in this review had reliable statewide cancer incidence data. State-specific behavioral data relied almost exclusively on the BRFSS. While many states attempted to supplement this with state-conducted surveys and research, the broad range of behavioral information necessary for effective public health planning and methodologic limits of the BRFSS[12] left most states in this analysis with insufficient behavioral information for planning. Similarly, little state-specific information on the determinants of behavior was available; the majority of this information was gathered from the research literature.

Almost all study states reported cancer-related health data by numbers and rates of deaths and cases, and behavioral data by tobacco use prevalence and screening frequency measures. Variability across study states was observed primarily in the use of certain measures, such as relative risk, years of life lost, and early-to-late stage ratios. Differences in measures and analyses reflected individual and coalition preferences as well as differences in data availability, analysis

capacities and resources. Comparisons of health and behavioral measures across demographic groups, cancer sites, geographic regions, and over time provided important information about the relative magnitude of the cancer problem and provided the basis for focusing planning efforts. Staff commented that while some of the very basic decisions guided by their data analysis—such as what cancers to target—could have been made based on existing national data, extensive analysis of state-based data provided a state-specific basis for targeting populations or regions in the state, identifying barriers to cancer control, and influencing policy makers and the public.

Greater variability and more limitations in the sources, measures, analyses, and use of data across sties was evident for environmental and health services information. Health services utilization data, for example, emphasized treatment rather than prevention services, and information on preventive health resources and existing programs had to be compiled from numerous independent sources. These data were more limited in their usefulness for planning and the sources of these data more scattered than health or behavioral data. Unlike health and behavioral data, which were consistently used to emphasize the magnitude of the cancer problem and identify high risk groups for intervention, environmental and health services data were used in many different ways across states to guide public health planning decisions.

While data clearly guided several important public health planning decisions, there also were notable limitations in the use of data to guide planning decisions. Once specific cancers, target populations, and general barriers had been identified, available data often fell short of being able to assist in identifying specific barriers within target populations and determining what proven intervention models should be implemented. For example, in one study state, high mortality and late-stage incidence rates identified cervical cancer as a problem. Subgroup analyses further narrowed the problem to low-income women in one region of the state and behavioral data supported underutilization of screening. Review of existing services data suggested that low cost PAP tests were available but were not being utilized. These data provided considerable focus for a cervical cancer intervention addressing the needs of low-income women in one region of the state. What remained less clear, however, was why available low-cost services were not being used. Were women unaware of

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the need to get a PAP test, were they unaware of the availability of low cost PAP tests, was the procedure in conflict with cultural beliefs, did they have access to these services, were they accessing other services, were physicians unaware of the need for or availability of PAP screening? Although some of this information would be expected to come from formative evaluation and community analyses, additional state-specific behavioral, environmental, and services data in this early planning phase could provide more focused characterization of the nature of the cancer problem and thus provide a stronger foundation for making public health planning decisions and guiding formative evaluation efforts.

In part reflecting limitations in data availability, staff and financial resources, and in some circumstances technical capacity for analyses, uncertainty was often observed about how best to match intervention needs with intervention models having established efficacy. The majority of information about intervention components and their implementation and efficacy is captured in the research literature and often requires considerable effort and technical resource to gather and appropriately interpret. Some attempts have been made to distill this literature for public health application.[13] However, guidelines for the application of intervention research that provide decision criteria for more appropriately linking specific public health problems to the interventions that may resolve them and provide sufficiently detailed information about implementation of the intervention remain illusive. We observed this paucity of usable information about empirically proven interventions to be a major impediment to the effective translation of cancer control science into practice.

For most states this DBIR planning process represented the first time such an array of cancer-related information had been pulled together. As part of this process, states involved health professionals, researchers, technical experts, and public health advocates in working groups and on state coalitions. Project staff from study states indicated that the process of pulling this information together and involving working groups and coalitions in state decision-making about cancer prevention and control was as beneficial for planning and cancer control action as the data themselves. This process enabled a more complete characterization of the cancer problem in their state than had been previously developed and provided a forum for working with and involving important partners for cancer prevention and con-

trol interventions in the planning process. In several cases, this effort provided a planning model that was used to address other health issues, such as heart disease.

Finally, this process was clearly dependent on a national infrastructure for state cancer prevention and control planning. This infrastructure provided financial resources to conduct data analyses and planning, sources of data such as SEER, NHIS, BRFSS, and ACS Facts & Figures, and the scientific literature on cancer-related behaviors and their determinants as well as intervention efficacy, most reflecting federally supported research.

Conclusions

It is encouraging that in these five state programs, comprehensive cancer control planning efforts used a full range of major types of data, used appropriate and in some cases sophisticated measures derived from these data, and linked these data to decision-making for cancer control. The data-based planning process reflected here is consistent with that observed in other health areas,[14–16] and represents a critical beginning to the establishment of an infrastructure for effective translation of cancer prevention and control science into practice.[17,18] This analysis provides a framework for public health planners to identify the type of data likely to be available for cancer prevention and control planning at the state level, various measures that can be realistically derived from these data, and how these can be linked to public health planning.

This analysis also provides direction for future efforts to strengthen the public health infrastructure for cancer prevention and control. First, it is unclear to what extent data and capacity limitations affected public health planning, the effective application of cancer prevention and control interventions, and potential reductions in cancer morbidity and mortality. If none of these limitations had been present and additional data and resources were available, how would the planning process have differed: to what extent would it have made subsequent intervention efforts more effective, and to what extent would it have changed potential reductions in cancer morbidity and mortality? Additional analysis of the role of comprehensive public health planning for cancer prevention and control and the extent of planning necessary to effectively guide public health action would provide important information to federal and state planners for designing,

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prioritizing, and implementing cancer control programs.

Second, specific weaknesses in the sources, quality, and applicability of available data to cancer prevention and control can be identified. State-specific incidence data are incomplete; available health services utilization data emphasize disease treatment and provide little information about disease prevention; data on preventive health resources and existing programs are scarce and sources scattered; and while the scientific literature provides a rich source of information on behavior and its determinants, state-specific information necessary for program planning is limited. While some efforts to enhance available data and resources for analysis are underway, such as the Center for Disease Control and Prevention's Cancer Registries Program and NCI's Cancer Mortality Mapping and CAN*TROL software, many of the needs identified in this analysis remain unaddressed. Future efforts to address these needs should be considered in the context of further evaluation of the role of data-based planning and the extent of data necessary to effectively guide comprehensive cancer control planning and to contribute to the implementation of interventions that reduce cancer morbidity and mortality.

Third, the need for a system whereby the findings of intervention research can be more effectively linked to public health problems and planning decisions for cancer prevention and control has been identified. Detailed guidelines that provide information about procedures for intervention implementation are needed to ensure fidelity to proven intervention models. Also needed are decision criteria that can be used as a framework for linking proven interventions to defined problems.

Finally, federal-state partnerships that support maintenance of necessary data sources, provision of technical assistance in the analysis and use of data, and resources for analysis and planning activities must be maintained. The experience of the state programs reviewed here supports the idea that the DBIR program was successful in stimulating states to achieve initial steps toward the translation of cancer prevention and control science into practice. While it cannot be proven that this type of systematic planning would not have occurred without dedicated resources and expertise, all states participating in this analysis felt strongly that this partnership was critical to their planning process.

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