

# **Meeting Report**

## **Data for Cancer Control Planning and Evaluation: Partners' Meeting**

**Centers for Disease Control and Prevention  
National Program of Cancer Registries  
Comprehensive Cancer Control**

**Atlanta Airport Marriott, Atlanta, Georgia  
March 18 and 19, 2002**

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## Executive Summary

*Data for Cancer Control Planning and Evaluation: Partners' Meeting* was convened in Atlanta, Georgia, March 18–19, 2002. Its purpose was to provide a forum to discuss challenges and opportunities in the use and dissemination of data related cancer prevention and control in the United States. The meeting brought together experts with a broad range of experience in cancer surveillance and control, and provided them with a forum to 1) propose ideas for improved coordination of data collection, evaluation, dissemination and use; 2) identify opportunities for improvement; and 3) discuss priorities for action.

Speakers presented state and national perspectives on data needs and showcased a variety of projects and products currently in place that are designed to improve access to data needed for cancer control activities. Following the presentations, workgroups met to discuss, and make recommendations on, the following topics:

- Data Needs
- Formats and Locations for Presentation of Data
- Current and Future Availability of Data
- Strategies for Integrating Data in Cancer Control.

Each workgroup presented the results of their discussion and a summary of recommendations for participating organizations. These recommendations require further discussion and prioritization. The recommendations can be summarized as follows:

1. Work collaboratively to address issues raised during the meeting, while encouraging individual organizations to move ahead on issues that they see as of primary importance.
2. Recognize that many different types of data content are needed for planning and evaluating cancer prevention and control programs.
3. Recognize that there is a wide variety of potential users of the data and they have different skill levels as well as different information needs. Provide data formats and

presentations that respond to their specific needs, cultural perspectives, and data literacy levels.

4. Provide data for planning and evaluating cancer control programs in an accessible, easy-to-use format for the majority of users.
5. Assure the availability of standardized numerators and population denominators (especially for racial and ethnic population groups), and consistent rules regarding such topics as cell suppression.
6. Help potential users of the data to know where the data are and how to access, interpret, and use them; provide training in the interpretation and use of data for cancer control.
7. Balance the need for timely data with the need for data of high quality.
8. Balance the need for local area data with the need for stable, valid information and protection of patient confidentiality.
9. Don't reinvent the wheel; build on "lessons learned" by the small number of state health departments and national organizations that have cancer control plans, involving effective public-private partnerships, in place.
10. Develop a cancer control plan for the nation. The plan should focus on changing the behaviors (individual and societal) that lead to excess morbidity and death from cancer.
11. Assure the availability of uniform high quality data on stage of disease at diagnosis and cancer survival; these data are especially important for evaluating cancer screening programs.

Concluding remarks by meeting participants affirmed that the meeting was a start toward working together in a more coordinated manner to assure the availability of data on cancer. The meeting was a valuable forum for discussion. It resulted in a comprehensive listing of key issues, priorities, and gaps with regard to effective use of data for planning and evaluating cancer control programs. Many issues and concerns are now on the table and need to be addressed. A commitment to strategic thinking and a collaborative, coordinated response from all partners is needed in order to address these issues.

## **Introduction**

A meeting entitled *Data for Cancer Control Planning and Evaluation: Partners' Meeting* was convened in Atlanta, Georgia, March 18–19, 2002. Its purpose was to provide a forum to discuss challenges and opportunities in the use and dissemination of data related to cancer prevention and control in the United States. The meeting brought together experts with a broad range of experience in cancer surveillance and control, and provided them with an opportunity to 1) propose ideas for improved coordination of data collection, evaluation, dissemination and use; 2) identify opportunities for improvement; and 3) discuss priorities for action. Appendix A is the meeting agenda.

### **I. Welcome and Opening Remarks**

Moderator: Irene Hall, PhD, Centers for Disease Control and Prevention

Donna Stroup, PhD, MSc, Assistant Director for Science of the National Center for Chronic Disease Prevention and Health Promotion, CDC, welcomed the group and reminded them that effective cancer surveillance requires collaboration between state health departments, academic experts, federal agencies such as the National Cancer Institute and CDC, the American Cancer Society, and multiple private partners. During this conference the group will:

- Discuss strategies to integrate data into cancer control plans;
- Identify gaps and approaches to bridging those gaps;
- Investigate dissemination strategies made possible by the Internet;
- Discuss data quality concerns;
- Explore analytic methods;
- Consider the contribution that Geographic Information Systems (GIS) can make to cancer-related decisions; and
- Discuss techniques to more effectively reach partners in cancer control.

Nancy C. Lee, MD, Director of the Division of Cancer Prevention and Control, CDC, in opening remarks, advised that the purpose of this meeting is *to promote planning and collaboration among organizations involved in cancer control at the national, state, and local level*. The desired outcome is *to complete a set of draft recommendations for integrating data and assuring information availability*.

Dr. Lee also advised that there are four reasons to hold this meeting at this time: 1) widespread adoption of state-based comprehensive cancer control; 2) the increased availability of cancer incidence data as more state registries meet national quality standards; 3) the increased availability of other cancer-related data; and 4) an expected increase in the cancer burden in coming decades as a result of growth and aging of the U.S. population.

## **II. Data Needs for Comprehensive Cancer Control**

Moderators: Sarah Landis, MPH, and Bruce Black, PhD., American Cancer Society

Attendees gave brief presentations on a variety of topics. A summary of each presentation follows.

### **A. Session Overview**

#### **Bruce Black, PhD, American Cancer Society**

Dr. Black raised the question as to why we need quality data. We need quality data to improve the quality of decision-making. Quality data can: 1) describe the problem, identifying the nature, causes, and needs of the cancer burden; 2) guide action by facilitating the identification of priorities and expected outcomes; 3) evaluate intervention programs; and 4) influence others to provide needed resources and support. Several state, national, and local data sources exist to describe the cancer burden as well as risk factor and screening behaviors related to cancer. However, more comprehensive and multi-level (e.g., local, state, regional, and national) data related to awareness and knowledge about cancer, policies, school and health care systems, occupational and community data are needed. In addition, we need to use high quality data as we move to action,

developing priorities based on the data and real-life feasibility. Appropriate indicators are needed to monitor outcomes using regular and ongoing data collection. Persuasive and provocative data can motivate people to action and are useful in obtaining political and financial support.

## **B. Comprehensive Cancer Control Planning**

### **Carol Callaghan, MPH, Michigan Department of Community Health**

Ms. Callaghan questioned how individual states are dealing with the issue of data. In 1995, the Michigan Cancer Consortium ([www.MichiganCancer.org](http://www.MichiganCancer.org)) developed a public/private coalition with the goals of significantly reducing cancer mortality and morbidity; establishing and maintaining a collaborative process; and achieving cost-effective resource allocation. The road map for the initiative was data collection, analysis, prioritization, strategic plans, commitments, implementation, evaluation, and celebration. The focus was on 5 major cancers, examining cancer burden, cost, behavioral and research data, and summarizing the data annually. The consortium developed a comprehensive cancer plan ranking objectives by importance and feasibility before obtaining commitments from each of the 60 member organizations. Ms. Callaghan outlined gaps and challenges, described outcome and process evaluations, and shared copies of the first annual report.

## **C. Chronic Disease Indicators**

### **Donna Knutson, MEd, Council of State and Territorial Epidemiologists**

Accurate and consistent estimates of disease burden and risk factor prevalence are the foundation for sound public health policy and programmatic activity to prevent and control chronic disease. Chronic disease surveillance, and hence public health policy, is enhanced with commonly defined surveillance indicators, data sources, and definitions. In 1997, three different organizations, the Council of State and Territorial Epidemiologists (CSTE), the Association of State and Territorial Chronic Disease Program Directors (ASTCDPD), and the National Center for Chronic Disease Prevention and Health Promotion of the Centers for Disease Control and Prevention (NCCDPHP, CDC), began an effort to identify a model list of chronic diseases, conditions, and risks

that should be placed under surveillance at both the state and national levels. These *Chronic Disease Indicators* are a minimum set of indicators that utilize data sources and surveillance capacity available to most states.

The partnership directed and managed a two-year process that eventually led CSTE to adopt what came to be known as the *Chronic Disease Indicators*. Criteria for selection of the indicators included 1) the public health burden of the disease or condition; and 2) the availability of high quality data on the disease or condition, especially at the state level.

These chronic disease surveillance indicators serve important purposes for chronic disease program directors and epidemiologists, as well as for state health agencies in general. They provide an operational definition for chronic disease surveillance capacity. Every state should have, maintain and utilize the ability to collect, analyze and disseminate the data from this minimal list of indicators on a regular basis. Assessing the existence and utilization of this capacity will help states and programs develop strategic and organizational plans. The indicators provide a minimal set of chronic diseases, conditions, and risk factors that should be under surveillance. Other indicators or alternative data sources may be added as necessary and appropriate. The chronic disease indicators should be included in strategic plans for public health. They will help bring consistency to temporal analyses or comparisons between different populations and between states. Estimates from these indicators can also serve as benchmarks for state and national programmatic activity.

In 1999 and 2000 the indicators for chronic disease surveillance were published in 2 volumes. The first volume describes the indicators and the second volume presents state-specific data for each of the indicators. The volumes and the data are available at <http://www.cste.org>.

This presentation included a demonstration of the Website display of the Chronic Disease Indicators.

### **III. Data Sources and Systems: State and National Perspectives**

Moderator: B. Sue Bell, PhD, National Cancer Institute

#### **A. Session Overview**

#### **B. Sue Bell, PhD, National Cancer Institute**

Dr. Bell explained the concept of the three-layer architecture of the data warehouse. The first level, known as the operational level, is represented by the cancer registries responsible for data collection and validation. The second level, known as the business data warehouses, is represented by systems such as CDC's WONDER and NCI's SEER Public Use file that provide access to reconciled data. The third level, known as business information warehouses, is represented by the American Cancer Society's E-Tool Planning CD-ROM and the State Cancer Profiles system being developed by NCI and CDC that combines data from across systems often as precalculated values such as age-adjusted rates.

Historically, databases evolved as stove pipes representing the organization (e.g. vital statistics for births and deaths, cancer registries for incidence, U.S. Bureau of the Census files for demographic data). But, to better address customers' information needs, information systems should cut horizontally across organizations. The American Cancer Society's E-Tool Planning CD-ROM and the State Cancer Profiles system are examples of cross-cutting information systems because they include statistics on cancer incidence, cancer risk factors, cancer screening coverage, and population data organized to support their customer's information needs.

The following presentations discuss data sources and systems first from the state perspective and then from the national perspective.

## **B. The Massachusetts Central Cancer Registry**

### **Susan Gershman, PhD, Massachusetts Cancer Registry**

Dr. Gershman described the goal of the Massachusetts Cancer Registry (MCR) which is to be an enhanced resource to the public and health care professionals for improving 1) cancer treatment; 2) health care for medically under-served populations; 3) cancer control planning; and 4) personal decision-making. The MCR is currently involved in three related projects:

- Massachusetts Cancer Central is an enhancement to the MCR website with 3 ports of entry: geography, life cycle stage, and a cancer site. The Web site allows the public to easily access information needed for personal decision-making.
- The Geographic Information Systems (GIS)/ Special Populations Project is conducting reabstracting audits to evaluate the validity of race and Spanish surname variables on MCR case reports and identifying areas with significantly high proportions of late-stage diagnoses of breast, prostate and colorectal cancers.
- The Treatment Patterns Project is undertaking a Pattern of Care Study that will focus on the extent to which the standards of care for female breast cancer advocated by the Women's Health Network have been employed in the treatment of a sample of patients with breast cancer drawn from the Massachusetts Cancer Registry.

The GIS/Special Populations Project and the Treatment Patterns Project will enable the Massachusetts Department of Public Health to work toward ensuring that all state residents receive quality cancer screening, diagnosis, and treatment services.

In addition to these 3 projects, the Massachusetts Community Health Information Profile available at <http://masschip.state.ma.us/> provides community health statistics to users who have signed a data release form.

### **C. The New Jersey Central Cancer Registry**

#### **Betsy Kohler, MPH, New Jersey State Cancer Registry**

A Cancer Registry can be used for incidence, stage, mortality, and survival data, and can provide expertise in data use. It can be used to establish baselines and make comparisons. As New Jersey set health objectives for 2010, the cancer registry database was used to set realistic and ideal targets, monitor progress, and measure the elimination of disparities. New Jersey is making use of new measures such as changes in incidence rates and changes in the stage of disease at diagnosis. GIS analysis will permit direct use of registry data for cancer control. Other tools available include the CSTE/CDC Chronic Disease Indicators, the NCI/CDC State Cancer Profiles, analyses that show penetration of the population by cancer-related services, examination of patient survival, and monitoring of standard or state of the art treatment. Creativity is called for in identifying and adopting new methodologies and uses of data, and in developing coalitions and partnerships.

### **D. Missouri Information for Community Assessment (MICA)**

#### **Jeannette Jackson-Thompson, PhD, Missouri Department of Health and Senior Services**

Dr. Jackson-Thompson presented a background on the Missouri Information for Community Assessment System (MICA) system (<http://www.dhss.state.mo.us/MICA/nojava.html>) and described the development of state-specific Behavioral Risk Factor Surveillance system (BRFSS) and cancer incidence MICAs. The objective of MICA is high quality data that is accessible to planners, evaluators, researchers, etc. Dr. Jackson-Thompson demonstrated the ease of use of their Web-based data system, describing the current layout and future plans. MICA allows users to create tables showing cancer incidence by year, age, sex, race, cancer site, stage, grade, and/or geographic are such as state, district/region, and county. Dr. Jackson-Thompson showed examples of three different MICAs, each compiled of data from different regions and for different cancer sites, pointing out how data can be selected and filtered or results requested using different criterion. There are many more advantages than disadvantages to the MICA system. The MICAs 1) make BRFSS and cancer

incidence data more readily available to more users; 2) lessen the burden of providing data to epidemiologists and for cancer inquiries; and 3) have resulted in a re-evaluation of confidentiality and cell suppression procedures.

#### **E. Access to Cancer Data: A Federal Agency Perspective**

##### **B. Sue Bell, PhD, National Cancer Institute**

Dr. Bell reviewed some current resources for cancer and health data and then introduced the State Cancer Profiles Website that is in development. She showed and explained Websites of not-for profits and federal agencies that currently provide health data. Some refinement opportunities would be to include measures of reliability and to provide visual summaries. An objective of the State Cancer Profiles project will be to present the cancer burden in a standardized way targeted to health planners. The web pages for the State Cancer Profiles Project outline various topics including the following: contributions to recent trend in overall cancer by the major cancer sites, long-term trends in mortality rates, comparison of rates and screening factors among states or among counties within a state, and estimating the size of potential target populations. In the future, users will be able to control classifications with sliders and view risk factor data by county.

Challenges include ensuring correct interpretation of data; balancing the contradiction between decision support and presentation graphics; complying with Section 508 of the Rehabilitation Act for web accessibility; and staying on the leading edge of technology. The prototype will be evolving over the next few months with possible deployment of some components during the second half of 2002.

#### **F. Planning Tool (E-Tool Planning CD-ROM) of the American Cancer Society**

##### **Sarah Landis, MPH, American Cancer Society**

Since 1999, the American Cancer Society has been implementing an outcomes-based, data-driven cancer control planning model at the state and local level. The E-tool is an easy to understand, interactive CD-ROM that was developed to assist local field staff and volunteers in completing comprehensive cancer control community assessments. Step 1 contains demographic, incidence, mortality, and behavior data. Step 2 collects data for profiles of the medical community, while Step 3 does the same for the non-medical

community. Step 4 is an activity summary, which displays reorganized input by cancer site. Using data from the local community, Step 5 assists in the analysis of the cancer burden, at-risk population, community capacity, opportunities for collaboration, and gaps and opportunities for action in the community. Step 6 easily generates specific reports or summary reports that can be exported into any word processing software for the planner's use.

## **G. Cancer Control Products Data Base**

### **Jon Kerner, PhD, National Cancer Institute**

Dr. Kerner spoke about closing the discovery/delivery gap. So often the products of research do not filter down to the professionals who are in the field trying to reduce the cancer burden. To close the research discovery/delivery gap, the National Cancer Institute has developed the Translating Research into Improved Outcomes (TRIO) Program. This program is focusing on three areas: using surveillance data, increasing access to evidence-based interventions, and addressing infrastructure barriers. As part of the TRIO program, Knowledge Transfer Teams are being developed in National Cancer Institute branches to review published research findings in order to identify areas where a sufficient number of good quality efficacy trials provide potential for lessons learned. Staff members also review existing portfolios of investigators with established intervention studies in order to create an entrepreneurial model or incentive to plan ahead to disseminate the product they have developed and tested through research.

Another critical element of TRIO is an inter-agency partnership model where the members' strengths complement one another. The tools from this partnership can be viewed on a continuum from populations at risk to suggestions for what states and American Cancer Society divisions can do to reduce their cancer burden. These tools include:

1. The CDC/NCI State Cancer Profiles project that identifies the best target populations for interventions;
2. The ACS E-tool that identifies which organizations are already working with these high-risk populations;

3. The CDC Guide to Community Preventative Services that tells us conceptually which intervention approaches work;
4. The NCI TRIO Intervention Products website which will provide direct access to efficacious and available intervention products.

Finally, in order to evaluate comprehensive cancer control, NCI, CDC, and ACS are planning the Comprehensive Cancer Control Evaluation Fellowship Program, which will provide two-year pre-doctoral fellowships in comprehensive cancer control program evaluation. The plan is to ultimately tie these tools together through a Universal Web Portal with shared access and “branding” from ACS, CDC and NCI.

The features of the TRIO Intervention Products Database will be a user-friendly summary of the intervention program with intervention products that can be downloaded off the Web. The database will be searchable by population and setting and will include crude summary indices for strength of efficacy, implementation complexity, and quality of research evidence.

#### **H. The Data Web: A joint development project of the U.S. Census Bureau and CDC Robb Chapman, Centers for Disease Control and Prevention**

Mr. Chapman explained that the Data Web is updating CDC WONDER and moving the system to the next generation. The objectives of the Data Web are 1) to develop a broad data repository; 2) to provide complete, detailed data; 3) to deliver data to any application; and 4) to access data where it lies. Many organizations are putting out applications on different platforms, of varying functionality and quality and sporadic content, often duplicating efforts, with no standard for exchanging data, and no search capability. The Data Web would be a delivery service, or portal, that would support all platforms. The data owners would publish data and the Data Web would locate and retrieve data from where it lies. Target audiences include the public, decision support staff, and researchers, each of which has varying degrees of expertise. Thus, both ease of use for the naive and highly detailed applications for those at the other end of the spectrum are needed.

Collaboration is under way with Data Ferret, a product of the Census Bureau for advanced systems for people who want to do exploratory analysis. The Hot Report takes results and packages them into a visual report. Objectives for 2002 include having 12 datasets from CDC available and the SF1 from Census 2000. In addition, collaboration is being sought with the Environmental Health Tracking Project, a similar program.

#### **IV. Summary Statement: State and National Perspectives**

Moderator: Vivien Chen, PhD, North American Association of Central Cancer Registries

**Panel Members: Jean Chabut, BSN, MPH, Chronic Disease Directors; Donna Knutson, MEd, Council of State and Territorial Epidemiologists (absent); Gary Edwards, MS, CHES, National Association of County and City Health Officials; Dee West, PhD, National Coordinating Council for Cancer Surveillance.**

Dr. Chen expressed excitement about potential systems under construction and emphasized the importance of the integrity and consistency of the data. It is especially important that the numerators be consistent. A concern is that different reporting times for different databases will lead to inconsistent reports because of the timing differences. The challenge is to ensure that good, meaningful data are disseminated correctly to health care providers and the general public at the local level, and that the data cover the continuum of the disease all the way from risk factors to quality of life and survival after diagnosis.

Ms. Chabut stated it is mind-boggling to imagine the amount of data available and equally mind-boggling to envision the work needed to make it user-friendly. We will need professionals to analyze and translate data reports. Data can be used to identify geographic areas where program policies are most supportive. For many cancers we can set feasible objectives using GIS mapping. We should involve legislators. Federal agencies should cooperate to supplement new discoveries with sufficient resources and guidance.

Mr. Edwards remarked that we have come a long way in the dissemination of data. We need more data at the community level. When data are released users should be encouraged to contact the Public Health Department for further information or interpretation. Numerators from the various data sources must be consistent. We need to focus on effective behavior change methods, risk factors, and ways to reduce the prevalence of risk factors. Make sure that health professionals know where to find the data and how to access it! Some local health departments that are still without Internet access are using Health Alert funding to get Internet access.

Dr. West reminded attendees that information is power. Lack of information is lack of power. Misinformation is chaos. We must keep a balance on data at a community level. The concept of putting data together to get a total picture is good. Consistency between reports and data is very important. Be careful not to publish incomplete data; achieve a balance between completeness and timeliness. Keeping data up to date is difficult because of constant change and resource requirements. There seems to be duplication of effort. One official dataset may be a good idea. Training is needed to interpret data. Population differences highlight the fact that one product does not fit all. Information needs to be diffused to the local community in order to be effective. Plan around providers and ethnic and cultural groups, not just systems and organizations. Don't violate confidentiality. Since apparent cancer "clusters" can occur randomly, be careful about using mapping.

## **V. Charge to the Workgroups**

**Phyllis Wingo, PhD, MS, Centers for Disease Control and Prevention**

**Brenda Edwards, PhD, National Cancer Institute**

**Bruce Black, PhD, American Cancer Society**

The attendees were divided into 4 workgroups each day. On Day 1, two workgroups would address Data Needs and two groups would examine Formats and Location for Presentation of Data. On Day 2, two workgroups would address Current and Future

Availability of Data and two groups would discuss Strategies to Integrate Data into Cancer Control Plans. The charges to the workgroups were described as follows:

### **A. Data Needs**

The purpose of this workgroup session is to discuss and determine data needs as they relate to the following topics:

1. Identifying cancer control needs and for setting of priorities
2. Developing cancer control plans
3. Tracking cancer control outcomes
4. Evaluating cancer control programs

The identified data needs will then be considered in light of data sources, and needs by different geographic levels, demographic factors, and timeliness.

### **B. Current and Future Availability of Data**

The purpose of the Current and Future Availability of Data Workgroup is to develop ideas to improve the future availability and accessibility of data for cancer control planning and evaluation. This includes ideas to inform the development of standards for future dataset design to improve accessibility of data to a diverse set of users with different information needs.

The Workgroup will brainstorm ideas regarding the following four linked issues:

1. What data are currently available for cancer control planning and evaluation?
2. How accessible are the current formats of data, and what changes to format need to be made to increase accessibility in the future?
3. What current special requirements, skills, or knowledge are required to access current data, and what changes need to be made to increase accessibility in the future?
4. What are the current characteristics of the data, and what changes need to be made to increase accessibility and usability in the future?

### **C. Formats and Locations for Presentation of Data**

The purpose of this workgroup is to discuss what needs to change in the where and how of data presentation in support of cancer control. Initially, only large organizations like the federal and state partners had the information technology (IT) resources to warehouse and disseminate national health statistics. The IT revolution and, in particular, the Internet have enabled all the partners to take an active role in providing information for their constituents. We have evolved without a strategic plan or the infrastructure to control the duplication. This workgroup would address the following questions:

1. Where do data warehouses for cancer control currently reside? Who are the sponsors? How and to whom is the data from those warehouses disseminated?
2. What are advantages of and issues with redundant data warehousing? What are potential approaches for addressing the issues?
3. Are there important audiences for whom there is no suitable data presentation currently being provided? If so, what formats are needed for those audiences?
4. How can we resolve the mismatch that exists between the need for "small area" statistics for planning and the public's right to know and the mandate for data providers to ensure patient confidentiality and data reliability?
5. In an ideal world, at what locations would the data reside and in what formats would it be made available?
6. How do we get there?

### **D. Strategies to Integrate Data into Cancer Control Plans**

Through a review of data use tools and data use priorities from Comprehensive Cancer Control Leadership Institutes, develop: 1) recommendations to enhance usability of proposed tools for use in state cancer control planning, implementation, and evaluation; and 2) strategies to increase demand for using data and research evidence at state and local levels. Create specific recommendations for integrating appropriate data and intervention research evidence into cancer control plans. Include strategies related to:

1. Sources and types of data that should be used;
2. Data gaps and strategies to bridge those gaps;

3. Coordination of various data and research partners; and
4. Effective use of data and research evidence to make the case for engaging in comprehensive cancer control efforts.

## **VI. Workgroup Presentations, Day 1**

Moderator: Brenda Edwards, PhD, National Cancer Institute

### **A. Data Needs, Table 1.**

Michael Thun, MD, gave a short presentation of the notes produced by participants at the first table. Reporting on data needs, he advised that data needs are divided into three sections: 1) data needed to characterize the current situation; 2) data needed to develop cancer control plans; and 3) data needed to evaluate progress.

The group identified the following minimum core cancer data:

- Stage at diagnosis and the ability to monitor changes over time in stage at diagnosis
- Information on all types of cancer-related risk factors
- Access to screening and treatment
- Knowledge, attitudes, and beliefs of patients and providers
- Costs of treatments, screening, disease burden
- Available services in the community for particular cancers
- Surveillance of cancer treatment, patterns of care
- Co-morbidity and treatment
- Quality of life and end of life care.

Dr Thun talked about the characteristics of high quality data, which include data completeness; comparability over a time period; an ability to measure trends for a geographic area; adequate labeling and interpretation; timeliness; adequate checking and validation; reduced fragmentation. Also needed in high quality data systems is the ability to integrate different types of data and an appropriate balance between depth and breadth

of information. We need to resolve the conflict between the desire for local data and the real limitations on interpretation of data from small areas. In addition, there may be a need for oversampling in special populations

As far as cancer control plans, some important tasks the group identified were: 1) identifying stakeholders; 2) identifying ways to get information to stakeholders; 3) sharing information across states; 4) building infrastructure for accessing data related to surgical staging, access to clinical trials, etc.; and 5) setting priorities and monitoring progress.

In the program evaluation area the group described the need for measures to 1) track program progress; 2) describe what programs actually do; 3) document the implementation of programs, measure program costs; 4) describe program impact with regard to knowledge, attitudes, behaviors, and systems changes. The group noted that it is important to report failures as well as successes.

## **B. Data Needs, Table 2.**

Susan Gershman, PhD, MPH, CTR, presented the notes produced by participants at the second table discussing data needs. The data needed by a cancer control program in order to identify which cancer(s) to address include the following: cancer burden; incidence; mortality; stage at diagnosis; survival; years of life lost; demographics; risk factor and screening information; treatment information -- who, when, where, and the standard of care; clinical trials in the state; rehabilitation; access to care; cost information of treatment, rehabilitation and palliative care; interest and knowledge of providers, the general population and legislators; systems and policies in place; effectiveness of policies and systems; quality of life issues.

## **C. Formats and Locations for Presentation of Data, Table 1**

Dr. Melanie Williams gave a presentation of the notes produced by the group. In response to the question, "What data warehouses are currently available for cancer control?" the group developed the following list:

Data Warehouses:

HRSA	SEER
The Consumer Product Index	NAACCR
State profiles	State cancer registries
The Council of State and Territorial Epidemiologists	NPCR
NCHS	ACS
The National Vital Statistics Data	The BRFSS
Some warehousing of cost data	YBRS
Medicare and Medicaid data	Atlas Plus
Wonder	Individual state vital records bureaus
	Hospital discharge data

The data from those warehouses are disseminated in a variety of ways including via the Internet, in printed publications, and as CDs, and may be geared toward the public as well as programmatic professionals and researchers.

Advantages of some redundancy in warehousing include multiple choices in formats and kinds of data, the geographic levels addressed, and the educational levels and sophistication required for use of the data. In addition, housing data at more than one location affords additional opportunities for validation of data.

Disadvantages of multiple data warehouses include:

- Discrepancies in data content and format
- Different geographic level presentations.
- Redundancy in the use of resources, finances and manpower
- Lack of standards
- Different cell suppression thresholds
- Different standards for population denominators and age standardization

- Unreliability of checks or validations
- Confusion for consumers
- Questions about validity of discrepant data.

Important audiences for whom there is currently no suitable presentation of cancer data in an appropriate format were identified, along with the following suggestions for suitable data presentations:

- For federal and state legislative staff – “hot reports”, fact sheets, pictorial, brief and simple;
- For the public, and particularly small communities - risk factors, qualitative information;
- For under represented ethnic and racial groups – appropriate and up-to-date denominator and numerator data, as well as culturally appropriate and sensitive information in a variety of languages;
- For the media - small community level analysis, a qualitative approach;
- For researchers – individual records, very detailed level data.

In order to resolve the conflict that exists between the need for small area statistics for planning along with the public’s right to know vs. the need to ensure confidentiality and data reliability, the following solutions were suggested:

- Aggregate the data and average across years.
- Suppress certain identifiers
- Utilize an institutional review board or other committee process for data release
- Respond to ad hoc requests as special reports.
- Use different statistical methods to look at smaller areas.
- Utilize a more in depth-needs assessment

The ideal formats and locations for presentation of data were described as:

- One system and one “number” for cancer
- A menu-driven user-friendly system

- Multiple formats in this universal system
- Shared data
- Real time data
- High quality data
- Standardized data
- Linkage to cost and clinical data

Some controlling factors in attaining these goals were identified as:

- Collaboration of different groups and consensus on policies
- Buy-in from all of the stakeholders.
- Shared accountability
- More funding
- More resources in general, and not just with regard to information technology
- More training
- Consensus and solutions with regard to confidentiality
- Ability to balance the public health needs with individual rights.

#### **D. Formats and Locations for Presentation of Data, Table 2**

Dr. Jeannette Jackson-Thompson presented the notes produced by participants at the second table discussing formats and locations for presentation of data. Adding to the previous group's notes, the group identified warehouses available to researchers, the public, communities, regional planners, local planners, and legislators. The principle disadvantage: the large number of warehouses is often overwhelming and confusing to the public.

On the question of redundancy, agreement was reached that the cost of design and maintenance, and non-comparability issues across states, are significant disadvantages. However, while this situation is confusing to the public, it was believed to be an advantage to some researchers.

Audiences that need better data support were identified as:

- Local policy makers at the city and county level, and even at the state level
- Cancer control planners
- Consumers (i.e., people and families with cancer and health care providers)
- Primary care doctors needing to know things about their service area and their clientele
- Local health officers, both city and county
- Coalitions and other community health organizations
- The media
- Legislators
- State health departments
- The disenfranchised by language and literacy.

The ideal situation was described as:

- Local data
- Smoothing formulas linking counties and missing data
- Federal supplementing of the states
- Collaboration to find the consensus and the critical audiences
- Location and format of data varied by audience
- Consensus about who are the priority audiences
- Attention and targeting of middle level and naïve data users
- User friendly formats
- Practical presentations of data
- A linked gateway site or a toll free number for access to critical information
- Critical questions asked by the web site of the user to target desired information
- Knowledgeable media
- Better infrastructure, including training and interpretation of data.

Some controlling factors include the need to:

- Add public and private partners
- Identify priority audiences

- Supply more information for the middle level and naïve users
- Complete the prototypes under construction
- Test usability of the prototypes with the priority audiences.

## **VII. Workgroup Presentations, Day 2**

Moderator: Catherine Hall, MPH, Arkansas Department of Health

### **A. Current and Future Availability of Data, Table 1**

Bruce Black, PhD, gave a short presentation of the notes produced by the first group. He explained that the group brainstormed data sets that cancer planners would use, producing a list of cancer data sets and databases.

For Disease Burden:

- NCHS
- SEER
- NAACCR
- NPCR
- State health departments

For Behavioral Risk Factors:

- NHIS
- BRFSS
- YRBS
- NHANES
- Adult Tobacco Survey
- Youth Tobacco Survey
- Current Tobacco Survey
- State databases
- Census

- HINTS
- HEDIS

For Environmental and Policy Risk Factors:

- ASTDR
- EPA
- PEW
- State Legislative Databases
- NCSL (National Counsel of State Legislatures)
- Health Care Systems data
- Tobacco, a CDC database

For Manpower Distribution and Occupational Exposures:

- SHIPP data
- SHEP data
- Nationwide policy surveys.

For Cancer Treatment:

- NCDB
- Medicare/Medicaid
- SEER link to the Medicaid
- Hospital discharge data
- State registry data on first course of treatment.

For Quality of life:

- ACS survey
- Special studies
- CANCORS
- JCAHO
- Cost

- Insurance
- Medicare/Medicaid.

Dr. Black cited weaknesses in policies regarding risk factors, systems behavior, and organizational behavior.

Some of the difficulties were identified as:

- Getting a sample of patients
- Incurring the expense of going through the cancer registries
- Working with an existing IRB or setting up and maintaining an IRB
- Understanding and meeting the terms of all the company's procedures and permissions
- Incurring the expense of performing any kind of nationwide survey
- Realizing the difficulty of getting a population-based survey
- Acknowledging that there are too many databases for a planner in a community or state to look at in order to determine what to do.

Dr. Black explained that the group looked at state planning going on now and local planning that will be taking place in the future. Some of the issues discovered were:

- Special knowledge is required
- Integration is required
- What kind of data do we need for planning?
- Community plans should mirror the state plans
- There are issues around incidence and mortality data as difficult to interpret
- While there are data at the state level on the behavioral risk factors, these are lacking at the local level
- At the local level there is a need for incidence and mortality data and resource information
- There is a deficiency in local-area data related to risk factors, interventions, community treatment patterns and access

- Local BRFSS surveys are expensive but doable
- The data are often not uniform when surveys are done in local communities
- Lack of community resources to do these surveys is an obstacle to availability and accessibility of those types of data at the local level
- Even if we have interventions that work, we don't necessarily know about them
- Local treatment patterns and access to treatment are important issues that would benefit from state and local planning.

A number of issues were addressed that affect the situation:

- The prioritization of funds
- Getting funds into BRFSS versus other places
- Confidentiality issues
- Data quality issues
- Access
- Uniformity of data

The group concluded that if a state profiles project were created that included the information currently in the American Cancer Society's E-Tool Regional Planning CD-ROM, a large proportion of the data that are needed immediately for cancer control planning at the state and local level would be available. In the hands of people who have the knowledge to analyze and use the data, availability of such data would be a significant step forward.

## **B. Current and Future Availability of Data, Table 2**

Jeannette Jackson-Thompson, MSPH, PhD, presented the notes produced by the second group discussing current and future availability of data. She explained that the group discussed two areas where needs were especially evident: behavioral risk factors and treatment. Some of the behavioral risk factor issues that were identified are:

- The difficulty presented by multiple points of access to BRFSS
- The access to YTS is very limited, and YRBS even more so
- Lack of local level data is a problem

- It is better to have a small quantity of high quality data that are available on a standardized basis.

Some of the special requirements identified around treatment are:

- Access to treatment data can be a challenge
- Understanding, analyzing, using, and recognizing the limitations of cancer treatment data are difficult
- Quality of life and end of life data are missing and needed
- As states expand in situ reporting to more non-hospital facilities, they may be inundated with data

There are needs for:

- Data integration
- Provider data
- Information about the providers
- Additional socioeconomic data
- Better access
- All kinds of local level data.
- Special software for analysis, along with training and interpretation expertise
- Standards for comparability
- Screening and guidelines data
- More data and uniform reporting requirements
- Assurance that every state has uniform, complete, timely, quality data on the basic cancer burden elements
- Uniform national reporting requirements
- Uniform national analysis standards
- Local level data but only for certain data
- Additional funding for states to collect local data
- Improved capacity in the states for analyzing and disseminating data

- Development of best practices and best standards for data collection and data analysis.

### **C. Strategies to Integrate Data into Cancer Control Plans, Table 1**

Linda Mulvihill, RHIT, CTR, gave a short presentation of the notes produced by the third group. The group developed the following list of needs and recommendations:

- A standardized format for morbidity/mortality data, with “hot reports” for naïve users
- The ability to compare data nationally on the state, regional or county level
- Databases linked to environmental, policy, and resources that are related to the success of cancer programs
- The ability of these different systems to track and archive queries to their databases
- The CDC and the ACS should integrate their data into a cohesive application database that can be used for local programming
- More expertise in data use and analysis
- Usable tools and accessible data
- Minimum computer specifications for all users
- NCI and perhaps CDC’s guides to community’s preventive services connected with intervention products
- A product database
- Improved communication to avoid duplication
- A summary of this meeting on a Web site, or maybe e-mail distribution; include a PowerPoint presentation; get on the speakers’ circuit for meetings; can also use newsletters of local health departments, NACCHO and state association newsletters, and other publications as communication tools
- Training to increase the capacity for use of the data
- Testimonials to influence using data in your cancer control plan
- Evaluations incorporated into interventions
- Rewards for using data in planning

- Incentives for including an evaluation plan in each program plan
- Accrediting facilities, such as the ACOS, JCAHO, NCI, and CDC require that the cancer control plan be used in order for the facility or organization to be accredited
- Refinement of the “peer county” concept.

#### **D. Strategies to Integrate Data into Cancer Control Plans, Table 2**

Leslie Given, MPA, gave the presentation of the notes produced by participants at the second table discussing strategies for integrating data into cancer control plans. The group identified the challenges as:

- Communication
- Collaboration
- Time
- Staff/capacity issues
- Funding and other resources
- Division of labor and the need for cross training
- A need for statistics, methodology, and software
- Timeliness and the comparative relevance of old data
- The balance of trying to anticipate and be prepared, but also taking advantage of what’s politically fashionable
- An integration of behavioral research with other forms of research
- Engagement of diverse populations in the local, state or even national arena
- Greater collaboration health departments
- Outreach in terms of external partners
- A belief in the shared nature of all data and a coordinated goal to use and integrate data
- Improved collaboration and communication within CDC to consolidate program areas in terms of responding for funding
- Better communication about the availability of new data
- Adequate staffing and time for analyzing the data

- Communication in layman's language in order to speak to a broader audience
- A connection with the broader community as resources in meeting personnel needs in a more timely manner
- Better methodologies, including information technology
- Education of politicians, partners and policy makers
- Use of partners such as ACS as a resource
- Relationships with universities, cancer centers, the community, the hospital registrars
- Engagement of survivor groups and provider and professional organizations
- More use of state medical journals, data reports
- Conferences such as this one
- Web based systems, query systems
- Regionalized data
- Integration of data on the cancer burden with behavioral data

## **VIII. Concluding Comments, Discussion, Next Steps**

Moderator: Ralph Coates, PhD, Centers for Disease Control and Prevention

Dr. Coates remarked on the innovative activities already in progress and introduced: 1) members of the National Coordinating Council for Cancer Surveillance who would give their final comments about future activities; and 2) Dr. Susan True, who would address some next steps.

### **A. Vivien Chen, PhD, North American Association of Central Cancer Registries**

Dr. Chen commented that everyone seems to have a good idea of data needs and availability, limitations of the datasets, and access to data. However, there are data that are not yet available, such as, quality of life data. There are data that need improvement, such as data on local communities. For small or frontier areas where reporting rates may not be adequate, the standardized incidence rate ratio (SIRR) could be an alternative measure. Communication and collaboration continue to be a challenge, as well as educating others, from our colleagues to politicians.

**B. Susan DesHarnis, PhD, American College of Surgeons**

Dr. DesHarnis remarked that we need to address how we can integrate the work of organizations and become true partners working in collaboration to achieve better data. We should involve clinicians to set standards and to do surveys. The National Cancer Data Base (NCDB) sponsored by the American College of Surgeons can provide information on practice patterns and outcomes. Private and public databases should be brought together.

**C. Brenda Edwards, PhD, National Cancer Institute**

Dr. Edwards commented that data for cancer control have progressed greatly, especially with respect to the amount of data and the number of people using it. Some of the biggest gaps that need to be addressed are the needs for 1) standardization; and 2) access to data while continuing to ensure confidentiality and informed analysis.

**D. Linda Mulvihill, RHIT, CTR, National Cancer Registrars Association**

Ms. Mulvihill commented that, from her perspective as the representative of cancer registrars, the standardization of denominators and timelines would be the best beginning. Also, continued communication, cooperation, and the sharing of ideas are critical in order to discover the best practices for data use.

**E. Phyllis Wingo, PhD, MS, Centers for Disease Control and Prevention**

Dr. Wingo commented that a single location providing access to multiple datasets and multiple sources of information would produce consistent statistics with standardized

data definitions and uniform cell suppression rules. This integration of government and private entities would eliminate duplicate work in developing warehousing and accomplish an efficient use of resources. While incidence and mortality data are necessary at all levels, Dr. Wingo stated she is not convinced that all data are needed at all levels, e.g., patient services information may be needed only locally. Workgroups have been successful for the Coordinating Council when an issue needs further study, particularly when technical expertise is called for, and are suggested for future topics.

**F. Dee West, PhD, National Coordinating Council for Cancer Surveillance (Chair)**

Dr. West advised that one must prioritize data needs and be creative in meeting these needs in order to maximize resources. We'll never have all that we want. For example, BRFSS at a level to provide local estimates would be costly, but using sampling such as is done with the Patterns of Care Study would be an alternative. There are improvement opportunities in the use, integration, presentation, and access to existing data. To improve presentation to the lay audience, data need to be consistent, meaningful, and have a market message. Information on the web should be culturally sensitive and presented at an appropriate literacy level. Needed is a national plan on how to change behaviors that lead to excess cancer risk. Another meeting should focus on the identification of what works and what doesn't work so that we will have an effective national cancer control program.

**G. Susan True, MEd, Centers for Disease Control and Prevention**

Ms. True summarized the meeting, laid out the next steps, and challenged the group to remain engaged in the process of discussing and improving the use of data. Clarification of the audience, their data needs, the level of desirable and achievable information, and the conflict between local level data and privacy protection are questions surrounding data needs. Regarding the locations and formats of data, conflicting and redundant databases, new formats for specific audiences, and real-time, standardized, linked, and customized data are questions. The data we need to carry out our current plans probably already exist, but might be difficult to locate and understand. Using data to evaluate

outcomes and interventions is a priority topic for the future. Training for cancer control planners is critical so they can appraise their priorities and strategies.

National partners should act on recommendations where possible. We continue to ask all to join in consensus building around some of the key issues, including defining the concept of shared accountability and exploring other ways to move forward. Comments and recommendations from this meeting will be collated and returned to the meeting participants for additional comments and then perhaps circulated more broadly. Ms. True concluded by providing the following reminder:

*“A journey of a thousand miles starts with a single step.”*

This meeting has been a step toward collaboration --.

## **IX. Conclusion**

Concluding remarks by meeting participants affirmed that the meeting was a start toward working together in a more coordinated manner to assure the availability of data on cancer. The meeting was a valuable forum for discussion. It resulted in a comprehensive listing of key issues, priorities, and gaps with regard to effective use of data for planning and evaluating cancer control programs. Many issues and concerns are now on the table and they need to be addressed. A commitment to strategic thinking and a collaborative, coordinated, response from all partners is needed in order to address these issues.

**Data for Cancer Control Planning and Evaluation: Partners= Meeting**  
**March 18-19, 2002, Atlanta, GA**  
*Atlanta Airport Marriott, 4711 Best Road, College Park, GA*

**AGENDA**

***March 18, 2002***

- 8:30 - 9:00      **Welcome and Opening Remarks**  
*Moderator: Irene Hall, PhD, Centers for Disease Control and Prevention*
- Welcome  
*Donna Stroup, PhD, MSc, CDC*
- Opening Remarks  
*Nancy Lee, MD, CDC*
- 9:00 - 9:50      **Data Needs for Comprehensive Cancer Control**  
*Moderators: Sarah Landis, MPH and Bruce Black, PhD, American Cancer Society*
- 9:00 - 9:10      Session Overview  
*Sarah Landis, MPH and Bruce Black, PhD, ACS*
- 9:10 - 9:30      Comprehensive Cancer Control Planning  
*Carol Callaghan, MPH, Michigan Department of Community Health*
- 9:30 - 9:50      Chronic Disease Indicators  
*Donna Knutson MEd, Council of State and Territorial Epidemiologists*
- 9:50 - 10:10      **Break**
- 10:10 - 11:30      **Data Sources and Systems**  
*Moderator: Sue Bell, PhD, National Cancer Institute*
- 10:10 - 10:15      Session Overview  
*Sue Bell, PhD, NCI*
- State Perspectives
- 10:15 - 10:40      The Central Cancer Registry Perspective  
*Betsy Kohler, MPH, New Jersey State Department of Health and Senior Services, and Susan Gershman, PhD, Massachusetts Cancer Registry*
- 10:430-11:00      Missouri Information for Community Assessment (MICA)  
*Jeannette Jackson-Thompson, PhD, Missouri Department of Health*

National Perspectives

11:00 - 11:20 Access to Cancer Data: A Federal Perspective  
*Sue Bell, PhD, NCI*

11:20 - 12:30 **Lunch**

12:30 – 1:40 National Perspectives (cont'd)

12:30 – 12:50 Planning Tool of the American Cancer Society  
*Sarah Landis, MPH, ACS*

12:50 - 1:10 Cancer Control Products Data Base,  
*Jon Kerner, PhD, NCI*

1:10 - 1:40 The DataWeb: A joint development project of U.S. Census Bureau and Centers for Disease Control and Prevention  
*Robb Chapman, CDC*

1:40 - 1:50 **Break**

1:50 - 2:15 **Summary Statement: State and National Perspectives**  
*Panel: Jean Chabut, BSN, MPH, Chronic Disease Directors; Donna Knutson, MEd, CSTE; Gary Edwards, MS, CHES, National Association of County and City Health Officials; Dee West, PhD, National Coordinating Council for Cancer Surveillance*

*Moderator: Vivien Chen, PhD, North American Association of Central Cancer Registries*

2:15 - 2:35 **Charge to the Workgroups**  
*Phyllis Wingo, PhD, CDC, Brenda Edwards, PhD, NCI, Bruce Black, PhD, ACS*

- \$ Data Needs
- \$ Current and Future Availability of Data
- \$ Formats and Locations for Presentation of Data
- \$ Strategies to Integrate Data into Cancer Control Plans

2:35 - 2:45 **Break**

2:45 - 4:15 **Workgroup Meetings**

Data Needs

## Appendix A

*Facilitators: Irene Hall, PhD, CDC; Mary Hutton, MPH, CTR, CDC; and Sarah Landis, MPH, ACS*

Formats and Locations for Presentation of Data

*Facilitators: Sue Bell, PhD, NCI; Dan Grauman, MA, NCI; Hannah Weir, PhD, CDC; and Paul Gargiullo, PhD, CDC.*

4:15 - 4:30 **Break**

4:30 - 5:15 **Workgroup Presentations**

*Moderator: Brenda Edwards, PhD, NCI*

### **March 19, 2002**

8:30 - 8:40 **Reminder of Meeting Purpose**

*Mary Hutton, MPH, CTR, CDC*

8:40 - 10:10 **Workgroup Meetings**

Current and Future Availability of Data

*Facilitators: Don Blackman, PhD, CDC, Robb Chapman, CDC, Bruce Black, PhD, ACS, and Deborah Holzman, PhD, CDC*

Strategies to Integrate Data into Cancer Control Plans

*Facilitators: Jon Kerner, PhD, NCI, and Leslie Given, MPA, CDC*

10:10 - 10:30 **Break**

10:30 - 11:15 **Workgroup Presentations**

*Moderator: Catherine Hall, MPH, Arkansas Department of Health*

11:15 - 12:00 **Comments, Discussion, and Next Steps**

*Moderator: Ralph Coates, PhD, CDC*

Comment by Members of the National Coordinating Council for Cancer Surveillance:

*Dee West, PhD, Chair; Vivian Chen, PhD, NAACCR; Susan DesHarnais, PhD, American College of Surgeons; Brenda Edwards, PhD, NCI; Linda Mulvihill, RHIT, CTR, National Cancer Registrars Association; Michael Thun, PhD, ACS; Phyllis Wingo, PhD, CDC*

Next Steps:

*Susan True, MEd, CDC*

# Data for Cancer Control Planning and Evaluation

## *Partners' Meeting*

March 18 & 19, 2002 • Atlanta Airport Marriott • Atlanta, GA

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