#### Contract No. 200-97-0088

#### Task 1

Essential Elements for Developing/Expanding Comprehensive Cancer Control Programs: Design Options for State Health Agencies

**Appendices to the Final Report** 

#### **Prepared for**

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Appendix C Methodology

### Appendix C Methodology

A case study protocol was developed to standardize study procedures as much as possible in all sites, and to maintain quality control of the research. The case study protocol contained criteria for selecting states, a definition of the unit of analysis for the study, the questions to be addressed, and procedures for data collection, data management and data analysis. This section describes the methodology that was used to prepare the case study protocol, and the subsequent research activities involved in conducting the case studies.

#### **Site Selection**

States were selected for this study based on characteristics of state programs that are expected to affect cancer control planning by SHAs. All states were described in terms of their previous experience with cancer control planning, the degree to which public health functions are carried out at the state or local level, the presence of an active cancer registry, and the resources available to support cancer planning activities. This was done using information from CDC reports, state documents, and interviews with knowledgeable persons at CDC, in states, and in private organizations. Following this, states were classified into three categories:

- *Comprehensive:* States had completed a comprehensive cancer control planning process and had implemented parts of their plan.
- *Planning Only:* States had developed a draft plan, but have not yet implemented it.
- *No Planning:* States that had not yet begun a planning process.

It was necessary that states in the last two categories be interested enough in comprehensive cancer control to assume the burden of cooperating in the case studies. Therefore, the "planning only" and "no planning" states were collapsed into a pre-planning category defined as states in which the SHA had not yet begun comprehensive cancer control planning but was contemplating doing so.

Within these two categories, two comprehensive and four pre-planning states were chosen to cover the range of characteristics that may influence the planning process. A distribution of states across important demographic and geographic dimensions was also sought. Michigan and North Carolina were selected as comprehensive states. Arkansas, Illinois, Maine, and Utah were chosen as pre-planning states. The rationale for choosing these particular states is summarized in Table C-1.

## **Unit of Analysis**

It was necessary to define a unit of analysis for the case studies that was general enough to be found in states at varying levels of development with regard to comprehensive cancer planning. At the same time, the unit of analysis needed to be specific enough to ensure that the study covered comparable activities in each state. For this case study, the unit of analysis was defined as the set of activities directed to the planning, design, implementation and evaluation of cancer

prevention and control programs by the SHA and its planning partners. These activities could be carried out by the SHA, other agencies within state government, local communities and/or public-private partnerships at the national, state or local levels. All of the data collection occurred with groups or individuals who had an existing or potential role in activities generated from the SHA and had coordinated at least some of their activities with those of the SHA.

#### **Research Questions, Study Questions and Instruments**

The research had two levels of questions: research questions and study questions. Research questions are the major topics that the case study addressed and are derived directly from the conceptual model. Study questions were designed to produce the information needed to answer the research questions during data collection and were used to develop study instruments.

Research questions for each of the model elements shown in Figure 1 of the report were:

- *Phase 1 Setting Optimal Objectives.* How has the SHA, in collaboration with its partners, produced a set of clear, data-based and operationally defined objectives for planning a comprehensive cancer approach?
- *Phase 2 Determining possible strategies*. How has the SHA identified program components that are scientifically likely to lead to achievement of program objectives?
- **Phase 3 Planning feasible programs.** How has the SHA linked program components to staff, resources and experience available in its own department, in other agencies of state and local government, and in the private sector?
- *Phase 4 Implementing effective programs.* What outcomes have resulted from implementation of activities resulting from the comprehensive planning process?

Two research questions were added to address the feedback and data components of the planning process:

- **Sustaining the planning process.** Have the outcomes of the process led to expansion and reinforcement of the comprehensive planning process?
- *Utilizing data resources*. Have planners appropriately and effectively mobilized, utilized and developed data to support comprehensive cancer planning in all steps of the planning process?

For each research question, more specific study questions were defined to describe the information needed to develop answers to the research questions. These study questions are included in data collection instruments and data sources are chosen to answer them. They also form the categories of a data analysis plan that will generate answers to the research question. Table C-2 presents the study questions that were used to support the development of instruments and links them to the research questions.

Instruments were produced by using a matrix to match study questions to categories of respondents and other data sources. In this way, instruments could be assessed for coverage of all study questions across all data sources, and redundancy could be built into the study

instrumentation to assure that the research questions were addressed from multiple perspectives by multiple informants. This also supported checks for reliability and validity of the data. At the same time, instruments were built with enough flexibility to accommodate the variability of states and to uncover aspects of the planning process that were not anticipated in the design of the study.

#### **Data Collection**

The majority of the data for this study were collected during site visits to states during which researchers met with SHA staff and other stakeholders in cancer prevention and control in the state. States were invited to participate in the study by CDC. Once a state had agreed to participate, Battelle contacted the SHA program director responsible for cancer prevention and control to arrange the site visit. States were provided with brochures describing the study for distribution to SHA staff, coalition members and others that were asked to participate in interviews or group discussions. State contacts were asked to suggest interviewees in each of the categories specified in the protocol. Either the state or Battelle arranged individual interviews at the direction of the state contact. The support of the state also was requested in setting up discussion groups.

Site visits began with an orientation for SHA staff during which the Battelle site visit team gave an overview of the project and answered questions from staff. Following this, there was an interview with the state program director. The site visit team then completed scheduled interviews and group discussions. The site visit ended with a debriefing with the SHA program director and other senior SHA staff to clear up ambiguities in the data and to discuss preliminary findings.

Data collection was guided by instruments tailored to individual states using a matrix of study questions and data sources as described above. Interviews were conducted with a variety of staff and community representatives involved in cancer planning. Persons interviewed included SHA staff from the organizational unit responsible for cancer programs, program directors and staff from other site-specific or risk factor-specific units, epidemiologists, and other staff responsible for data sources. Interviewees included members of community organizations and providers who deliver services to clients of public health programs. Individuals were interviewed who had been key players in the planning process or who the state program director believed would be key players in future efforts. In each state, discussions were conducted with groups of eight or fewer people involved with an actual or potential cancer planning process. Types of persons interviewed are tabulated for each state in Table C-3.

<sup>&</sup>lt;sup>1</sup> As part of instrument development, a request for clearance through Battelle's Institutional Review Board was prepared. This clearance was obtained prior to any data collection in states.

<sup>&</sup>lt;sup>2</sup> Site visits were conducted in March, April and May 1998.

<sup>&</sup>lt;sup>3</sup> All interviews were audio taped, if this was acceptable to the interviewee. Interviewees were assured that interviews and group discussion proceedings would be kept confidential and that individuals would be neither quoted nor attributed. Nor would tapes be made available to anyone outside of the project staff.

#### **Data Analysis and Reporting**

A project database was developed to support the preparation of case study reports. The database contained two major components: field interview data and documentary data. Document descriptions and summaries were prepared and organized into an Access database that served as a reference source in preparing reports.

Data collected during site visits were analyzed using NUD\*IST software. For each interview, a transcript was prepared and reviewed for accuracy by members of the field team. Data element codes were defined using the study questions as a guide. Interview transcripts were independently coded by a member of the site visit team and another member of the research team. Data were sorted by codes, and hard copy reports for individual topics were prepared. These data reports were used as input to case study reports for individual states and for the cross-site report. Descriptive case studies were prepared by summarizing data across all interviews for each study question or significant topic. The cross-site analysis was performed by comparing findings across comprehensive and pre-planning states for individual topics. Conclusions were then derived from these comparisons.

Prior to the cross-site analysis, descriptive case studies were returned to state program directors for review in order to verify facts and interpretations. All factual changes that emerged in state reviews were made. Differences in interpretation were discussed with state staff and an agreement was reached as to how to handle these in the report. Conclusions were not changed unless it could be demonstrated that facts did not support them.

**Table C-1 Case Study States by Site Selection Criteria** 

State	Development	Important Criteria	Rationale
Arkansas	PP	Independent agency with state health units; has state money for cancer control; BCCP for 3 years; cancer registry in planning phase. Urban population 54%; African American 16%; American Indian <1%; Hispanic <1%; 40 years or older 41%.	Meets need for diversity in characteristics; has strong staff with interest in comprehensive cancer control; large African American and rural population; state funding for cancer control; located in South
Illinois	PP	Independent agency with local health departments; cancer plan from 1989; DBIR state; BCCP for 5 years, cancer registry. Urban population 85%, African American 15%; American Indian <1%, Hispanic 8%; 40 years or older 38%	Commitment to beginning comprehensive cancer control; large state with dominant urban area and large rural territory; large African American . Hispanic populations; Midwest location.
Maine	PP	SHA component of a DHHS; all cancer located in one division of SHA; few local health departments; cancer plan from 1990; very interested in comprehensive cancer control; BCCP for 4 years; cancer registry; DBIR state. Urban population 45%; African American <1%; American Indian <1%; Hispanic <1%; 40 years or older 40%.	Commitment to beginning comprehensive cancer control; good health department capacity to plan; large dispersed rural population; low minority population; Northeast location.
Michigan	С	SHA component of agency that also includes Mental Health and Medicaid; local health departments; state money for cancer control; BCCP for 7 years; cancer registry. Comprehensive cancer plan being implemented. Urban population 71% urban; African American 14%; American Indian <1%; Hispanic 2.2%; 40 years or older 38%.	Strong infrastructure for cancer control; substantial experience with comprehensive cancer control planning; large urban population and dispersed rural population; large minority populations.
North Carolina	С	SHA component of a DHHS; local health departments; state funding for comprehensive cancer control; BCCP for 6 years; cancer registry; DBIR state. Comprehensive cancer control plan being implemented.	Strong infrastructure for cancer control; substantial experience with comprehensive cancer control planning; strong active planning

State	Development	Important Criteria	Rationale
		Urban population 50%; African American 22%; American Indian 1.2%; Hispanic 1.2%; 40 years or older 39%.	group; strong private sector support; large urban population and dispersed rural population; large minority populations.
Utah	PP	Independent SHA; local health departments; no state funding for cancer control; BCCP 4 years; SEER registry only; no existing plan. Urban population 87%; African American <1%; American Indian 1.4%; Hispanic; 4.9%; 40 years or older 29%.	Interest in SHA in beginning comprehensive cancer control capacity; strong private sector capacity. Large concentration of population in urban area with very dispersed rural population. Western state.

# **Table C-2 Study Questions Linked to Research Questions**

How has the SHA, in collaboration with its partners, produced a set of clear, data-based and operationally defined objectives for planning a comprehensive cancer approach?

- Can the SHA produce written objectives?
- Is there agreement on the objectives among the several groups of people who participated in developing them?
- What kind of needs assessment was conducted as part of the process for defining objectives most appropriate for this specific state?
- How are the written objectives supported by epidemiological, financial and health care utilization data? Are they prioritized on the basis of data?

How has the SHA identified program components that are scientifically likely to lead to achievement of program objectives?

- How were proposed interventions linked to the comprehensive planning objectives?
- How were proposed interventions evaluated relative to the needs assessment?
- Was there an effort to compare alternative intervention strategies to identify those most appropriate for the state?
- Were proposed interventions reviewed for scientific evidence of effectiveness, efficacy and cost effectiveness?

How has the SHA linked program components to staff, resources and experience available in its own department, in other agencies of state and local government, and in the private sector?

- What are the barriers to program implementation and from where do they come? How could these barriers have been addressed in this or earlier steps of the process?
- Is there evidence of an effort to bring into the planning process all of the important players from the SHA, other state and local agencies, and the private sector (e.g. voluntary organizations, providers, patient advocacy groups, health education professionals)?
- Is the organization of the coalition or group of players adequate to implement and maintain implementation of program activities?
- Have participants in the planning process contributed resources, personnel and expertise
  to the development and implementation of activities conducted as part of the
  comprehensive cancer control process?
- Is there evidence that linkages established during the planning phase have been maintained and or strengthened as the initiative has moved on to implementation?
- Are there gaps in the capacity of the coalition of planners to accomplish what they have set out to do? How could these be addressed?

#### What outcomes have resulted from implementation of comprehensive planning?

- What programs have been developed and delivered?
- Are there data to demonstrate that they are being delivered appropriately to the target population?
- Have any evaluations been done and what have these shown about the effectiveness and cost effectiveness of program implementations resulting from the plan?
- Is there any evidence that site-specific or risk-factor specific programs have been implemented as part of a comprehensive planning process (e.g. cross-referral, exchange of informational materials, etc.)?

# Have the outcomes of the process led to expansion and reinforcement of the comprehensive planning process?

- Has the planning process continued beyond its initial planning cycle?
- Is there any evidence of feedback of lessons learned from the prior planning cycle to the current one?
- What changes have occurred in coalition membership and functioning? Have there been changes in individuals or organizations participating and how has this affected processes and outcomes?

# Have planners appropriately and effectively mobilized, utilized and developed data to support comprehensive cancer planning in all steps of the planning process?

- Is there any evidence that program priorities are changed or adjusted to reflect shifts in needs of the population based on new data?
- What was the process used by the SHA to identify, analyze and apply data to each of the phases of comprehensive planning?
- Are there notable gaps in the kinds of data available? In the use of available data?
- Are those involved in the planning process well-informed about the role of data in effective planning? How have they been able to act on this information?

**Table C-3 Summary of Interviews conducted in Six Case Study States** 

	Arkansas	Illinois	Maine	Michigan	North Carolina	Utah
SHA Program Directors	5	6	6	3	3	6
SHA Administrative Officials	1	1	1	3	1	1
SHA Program staff	4	6	4	4	4	4
SHA Epidemiologists	1		1	2	1	2
Cancer Registry staff	2	1	2		1	1
Vital Statistics staff	1	2	1	1		1
Local HD or health unit staff			1			1
Planning group staff				2	4	
State legislators	1	2	1	1	1	
National health organizations	4	3	2		1	2
Consumer organizations	4	5		1		
Community organizations	2			2		

	Arkansas	Illinois	Maine	Michigan	North Carolina	Utah
Providers	1		2	1	2	2
Other <sup>4</sup>	2	1	1		3	
	28	27	22	20	21	20
Coalition leader (duplicate)	1		1		2 <i>d</i>	1d
Coalition members(duplicate)	1	7	7	5	5	

<sup>&</sup>lt;sup>4</sup>Other category includes university faculty and outside contractors supporting cancer prevention and control programs, a retired state official who had been part of early planning, and an unaffiliated coalition member who is a cancer survivor.

Appendix D Site Visit Protocol

# Case Study Field Procedures Contract No. 200-97-0088, Task 1

on

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> > March 31, 1998

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Battelle Centers for Public Health Research and Evaluation 2101 Wilson Boulevard, Suite 800 Arlington, VA 22201 This report is a work prepared for the United States Government by Battelle. Battelle endeavors at all times to produce work of the highest quality, consistent with our contract commitments. However, because of the uncertainty inherent in research, in no event shall either the United States Government or Battelle have any responsibility or liability for any consequences of any use, misuse, inability to use, or reliance upon the information contained herein, nor does either warrant or otherwise represent in any way the accuracy, adequacy, efficacy, or applicability of the contents hereof.

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# I. Preparing for Site Visits

This section covers (1) the study purpose and research questions, (2) data sources, (3) background information to review prior to beginning fieldwork, (4) the logistics involved in arranging the site visit, (5) procedures for developing customized interview instruments, and (6) a checklist of items to take into the field.

# A. Study Purpose and Research Questions

#### 1.1.1 Study Purpose

The purpose of the study is to provide CDC with technical support in their efforts to assist states with comprehensive cancer planning. This support will be accomplished through:

- A systematically collected and scientifically sound body of evidence on the current state of comprehensive cancer prevention and control initiatives in selected states,
- An evidence-based and flexible Organizational Design Options document that can be used by states at different levels in the planning process to support their comprehensive cancer planning initiatives,
- One or more scientific articles that will make the findings of this research readily available to public health professionals, private providers and the general public.

#### 1.1.2 Research Questions

To achieve the study objectives, a working model (Appendix A) has been developed showing how a comprehensive planning process would be expected to work to produce an integrated program approach to cancer prevention and control in state health departments. The model has four major phases:

- Phase I: Setting objectives
- Phase II: Determining program components
- Phase III: Planning programs
- Phase IV: Implementing program activities

The research questions are derived from this model and are as follows:

- How are cancer-related programs organized within the state health agency (SHA) and how do they interact with agencies or programs outside the SHA?
- How has the state health agency produced a set of objectives to guide the planning of cancer prevention and control programs?
- How has the state health agency identified program components likely to lead to achievement of program objectives?
- How does the state health agency set priorities and determine which program components can actually be implemented, given available resources and other contextual factors?
- How does the state health agency ensure the implementation of program components and assess whether goals and objectives are being met?
- Have the outcomes of the process led to expansion and reinforcement of the [comprehensive?] planning process?
- How have planners mobilized, utilized and developed data to support cancer control planning in all steps of the planning process?
- How have planners mobilized, utilized, and developed partnerships to support cancer control planning in all steps of the planning process?
- What are the barriers to comprehensive cancer control planning and implementation, and how should these be addressed?

Each research question has multiple study questions associated with it (see Appendix B) which are tailored to the state's current stage in the planning process. Each state is characterized as either a comprehensive planning state or a pre-planning state.

#### **B.** Data Sources

The three major data sources for this study are:

- Individual interviews,
- Group discussion interviews, and
- Supporting documents.

Each research and study question will be answered using data from one or more of these sources.

#### 1.1.3 Individual interviews

Individual interviews will be conducted with a variety of staff and community representatives involved in cancer planning. Operational definitions of each interviewee type are as follows:

- State program director The individual with supervisory responsibility for cancer prevention and control programming for the state health department.
- State/local health department program staff Staff directly involved in managing and/or implementing public health programs for cancer prevention and control. These may be service delivery programs, health promotion programs, or any intervention that might reasonably be expected to be an outcome of a comprehensive cancer planning process.
- Data management/epidemiology staff A person who is directly involved in collecting managing and disseminating public health data on cancer mortality, morbidity, prevalence, incidence or risk factor distribution. This may be someone from the cancer registry or a division responsible for surveillance. This person may come from the state health department or some other state agency. The defining criterion is that this person is involved in producing data on cancer in the state.
- Coalition head/member Persons who have been members of a coalition that has conducted or currently conducts state public health planning that incorporates cancer planning. The coalition may be involved solely in cancer planning or cancer planning may be one of several foci of coalition activity. An attempt will be made to identify a past or present coalition leader and at least one person who is a participant but not a part of coalition leadership.
- State legislator or staff person These will be individuals connected to the state legislature and familiar with factors affecting appropriations and funding of public health activities for cancer and other chronic diseases.
- *Community organization leader* These are members of private voluntary health organizations, grassroots organizations or patient advocacy groups with a stake in the outcome of comprehensive cancer planning.

Interviewee type	Minimum number of interviews	How interviewee will be identified	Is group format OK?	Approx. time needed
State program director	1	CDC	no	2 hours (1.5 day 1 0.5 day 3)
State/local health department program staff	2	State program director	yes	1 hour
Data management /epidemiology staff	1	State program director or by referral	yes	1 hour
Coalition leader	1	CDC or state program director	no	1 hour
Coalition member	1	State and local staff or coalition leader or CDC	desirable	Individual 0.5 hour, group 1 hour
State legislator or staff person	1	State program director or coalition leader or CDC	yes	0.5 hours
Community organization leader	2	State and local staff or coalition leader/members	yes	Individual 0.5 hour, group 1 hour

#### 1.1.4 Group discussion interview

A group discussion will be conducted with a group of eight or fewer people who have a demonstrable involvement with an actual or potential cancer planning process. It should focus on state health department staff who have been or will be key to any type of comprehensive planning process, including staff from site-specific or risk factor-specific units and data management and analysis staff. These people should be involved in the day-to-day implementation of plans and programs and ideally should not be at the supervisory level. The group discussion should be used as an opportunity, to the extent possible, to include people not otherwise interviewed.

Members of community organizations or providers who deliver services to clients of public health programs should only be included if they have been key players in the planning process (comprehensive states) or the state program director believes they will be key players and would like to include them (pre-planning states).

At least two suggestions for group members will be solicited in the initial contact with the State program director. We will add other members based on suggestions from other types of interviewees as they are recruited.

#### 1.1.5 Supporting documents

Supporting documents include both printed and electronic material with information specific to each state. Some documents have been obtained already, others will be requested prior to the site visit and still others will be solicited during and after the site visit.

Use the following table to help identify documents and keep track of what you can and do receive.

Document	Availabl e	Date rec'd
Draft or final cancer plans (or chronic disease plans) the department has produced		
Descriptions of the process through which these plans were produced		
Minutes of state-level cancer planning meetings		
Lists of state-level cancer coalition members and/or subcommittee members (or partners they would envision including in such a coalition)		
Lists of the types of data available to them for determining cancer burden and high-risk target populations		
Lists or descriptions of programs they have designed/implemented that cross categorical boundaries		
Other (specify)		
Other (specify)		
Other (specify)		

Information from these documents will be extracted using a standard **document summary sheet** (see Appendix H) derived from the research questions for this study. This will assure that documents from all states are treated to the same level of scrutiny.

# C. Background Information

- Background packet. Joanne Abed has prepared a background packet for each state and provided it to the team members participating in that site visit. This background packet contains any information that has been collected to date specific to that state.
- Literature highlights. Each team member has been provided with a bibliography of literature collected for the study. Those who want to prioritize their reading may want to focus on the recommended reading list provided in Appendix C.
- Other documents. To the extent possible, the team should seek to obtain other documents or background information from the state contact prior to the visit. Reading these documents may provide insights into key events that we want to make sure to cover during the interviews.
- Web sites. State health department web sites can be a source of information. Addresses

for some of the web sites have been identified, other web site URLs can be found at CDC Website's Links page.

Illinois: <a href="http://www.idph.state.il.us/home.htm">http://www.idph.state.il.us/home.htm</a>

Michigan: <a href="http://www.mdmh.state.mi.us/mdch2/aboutdch.htm">http://www.mdmh.state.mi.us/mdch2/aboutdch.htm</a>

North Carolina: http://hermes.sches.ehnr.state.nc.us/SCHS/main.html

Arkansas: http://health.state.ar.us/

Maine: <a href="http://www.state.me.us/dhs/main/welcome.htm">http://www.state.me.us/dhs/main/welcome.htm</a>

Utah: <a href="http://hlunix.hl.state.ut.us/">http://hlunix.hl.state.ut.us/</a>

#### D. Arranging the Site Visit

#### 1.1.6 Introductory phone call

Mary Odell Butler initiated contact with the states through a phone call to the state contact person (usually the Health Dept. Director) provided by Dr. Barbara Reilley. Dr. Butler has called the state contact person to personally thank them for their participation in the study, provide an overview of the study, describe in general terms what the site visit will involve, and to answer any questions they may have. She has asked them to start thinking about possible dates of the site visit but indicated that a designated Battelle contact person would be calling to handle logistic arrangements.

#### 1.1.7 Introductory letter

Dr. Butler followed up the phone call with an introductory letter to the state contact person. The letter reiterated the major points covered in the phone call. The name of the Battelle person who will serve as the contact for arranging the site visit was included in the letter as well as contact information for Mary Odell Butler and Barbara Reilley as the Project Director and Technical Monitor.

The letter also included copies of a tri-fold hand-out (brochure) about the study that could be provided to staff and other likely participants in the site visit describing the study, how states were selected, and what the site visit will be like. The brochure also included names and contact information for the Battelle contact for that state and for Dr. Butler and Dr. Reilley. A copy of the brochure is included in Appendix D.

#### 1.1.8 Follow-up phone contact

The designated Battelle contact person for each state should follow-up by phone with the state contact within 1 week of Dr. Butler's letter. The primary objectives of the call are logistical

#### in nature:

- Stress that we will undertake the scheduling and other logistical arrangements for the site visit to the extent possible to avoid placing a heavy burden on the state contact person. However, we will need assistance in key areas to ensure that we meet with the right people and come away from the visit with the information that we need.
- Set the dates of the site visit. It may not be possible to do this on the spot but encourage the state contact person to at least suggest a couple of options that can be pursued. The state contact may need to check with key players (and you may want to double check with your co-team member).
- Explain that we like to have a brief orientation meeting the first morning and a brief recap meeting with the coordinator/director at the end. These are optional but most states will probably want to have this.
- Request an organization chart.
- Identify potential interviewees and basic contact information for each person (name, position, organization, phone #). Review the list of types (and numbers) of people we want to talk to and work with the state contact person to identify the best people. If the state contact persons do not have all the answers right away offer to send a list for their use in putting together their recommendations. Alternatively, arrange a suitable time to call back.
- Identify group discussion participants, location, and time. Ask the state contact person if they have an appropriate room (accommodates 8 people, available, quiet). If not, locate a room nearby that can be used. Plan for 1 ½ 2 hours in length (reserve a room for 2 hours). If possible, find a time during the last day of the visit. Offer to contact all the individuals yourself but feel free to accept offers of help if they are forthcoming.
- Review document list and discuss the availability of these or other pertinent documents that the state may have. Request that copies be sent in advance if possible. Offer to send a fed ex envelope.
- Indicate that you will send a follow-up letter that summarizes the types of people we want to talk to and documents any decisions or action items agreed upon regarding dates of the site visit, other scheduling issues, or materials the state contact person agrees to provide. Encourage the state contact to call if anything is not clear.

#### 1.1.9 Follow-up letter

Prepare the follow-up letter described above. The letter should go out under the signature of the site visit team. Customize this letter based on the conversation and the needs of the state.

Remember that the purpose of the letter is not to overwhelm the state contact person or assign them tasks but to clarify the objectives of the visit and to help them understand what support we need so that all goes smoothly with the least imposition possible. If it is helpful, include a list of the types of people we want to interview and a list of the types of people we want to include in the group discussion. If the state contact has agreed to help with arrangements or send materials, this can be documented in the letter. Send a FedEx envelope if that would be helpful.

#### 1.1.10 Scheduling

Once the dates of the visit are set and the list of interviewees has been drafted, the site visit team is responsible for scheduling the interviews. One member of the team should be the designated scheduler for each site. Teams may choose to have one person do both sites or to each do one. In scheduling interviews it is important to emphasize that we prefer a quiet place where we can talk with minimal disruption.

- Orientation (optional). A brief orientation the first morning for interested staff approx. 30-45 minutes will provide the team an opportunity to give an overview of the study and to meet many of the staff members with whom subsequent interviews will be conducted. It also provides an opportunity to look over the schedule and adjust/confirm with people as needed.
- Group discussion meeting. If the state contact has agreed to set up the group discussion, great!! If not, the Battelle coordinator will need to contact the individuals recommended. Make sure the place and time are already set before contacting participants. The group discussion should take about 1½ hours but set aside 2 hours in the schedule (and for the room reservation).
- Individual interviews. One option, if it can be arranged, is to use the first morning for the orientation (45 minutes) and the interview with the director (1½ hours) and reserve the last afternoon for the group discussion (2 hours) and the de-briefing (1/2 hour). This leaves approximately 10 individual interviews for the remaining 2 mornings and 2 afternoons. The team may want to aim for 2 or 3 each morning and 2 or 3 each afternoon. Most interviews should last from ½ to 1 hour depending upon the number of questions that need to be covered, but it is always nice to allow an extra margin of time in the event someone has more to share than anticipated or unexpected interruptions slow down an interview. A good suggestion is to plan all off-site visits the 2<sup>nd</sup> day, thus scheduling the remaining Health Department interviews for the first afternoon and last morning. This would reduce the burden of the visit on the Health Department.

Computerized face sheets and forms (Appendix E) have been prepared for use in tracking participants. These include:

- 1. Site Visit Set—up Form,
- 2. Study Participant Face Sheet, and

#### 3. Group Discussion Face Sheet.

The face sheets are essentially electronic data entry forms that are part of the MS Access case study databases. The face sheet forms can be printed out and used in the office or field as hard copies. Each team member responsible for scheduling site visits has been provided with a database for their case study and a supply of hard copies. When scheduling interviews by phone, the scheduler should assign an ID# (see below) and record name, position, organization, contact information, address, interview schedule and instrument used directly onto the hardcopy of the **Site Visit Set—up Form** and then type it into the database. If an individual is scheduled to participate in a group discussion, then their ID# should be included among the participants in the group discussion(s) on the **Group Discussion Face Sheet** for their state. Before going to the state for the site visit, team members should print out clean copies of the **Study Participant Face Sheets** and **Group Discussion Face Sheet(s)** to take into the field. Corrections to information on the face sheets can be made by hand in the field and then corrections to the case study database can be made upon return. The database file with all correctly entered and updated information will then be provided to John Rose in Arlington who will maintain a centralized project database.

A daily schedule form (Appendix F) has also been prepared for use in laying out the schedule for the 3 days. The form allows team members to know at a glance where they are scheduled to be at various hours of the day, who they are meeting with, the instruments they need, and directions for getting to the interview. There is also a place for noting contact information in the event last minute adjustments become necessary.

#### **1.1.11 ID system**

An identification number system has been created for each person interviewed (ID#), for each group discussion (GD#), and for each supporting document (DOC#). The purpose of the identification system is to provide us with a means to identify each individual data source for the case studies, and to protect the confidentiality of respondents. The ID system is described in Appendix L.

Each study participant (interviewee and/or group discussion participant) and document should be assigned an identification number when they are brought into the study. Each group discussion should be assigned a number at the beginning of the set—up procedures. The identification number for every data source is recorded on the face sheet form and entered into the relevant case study database.

#### 1.1.12 Travel arrangements (air travel, hotel, car)

Each person is responsible for making his or her own travel arrangements. Ideally, only one car should be needed. However, if scheduling difficulties indicate that the team may have to split up during the course of the visit to conduct interviews in distinct locations, a second car may be required. The state contact may be better at suggesting hotels than Battelle Travel. Plan to arrive the night before to have 3 full days on site.

### **E.** Developing the Instruments

The interview instruments will be custom designed for each state prior to the site visit. The goal of the design process is to balance the need for a core set of standard questions addressed in all states with the need to be flexible and adaptive to the characteristics of individual states. The following procedures will help to achieve the balance of standardization and flexibility:

- 1. Use the matrix of research/study questions by data source (Appendix B) as the building blocks for the customized instruments. Use the appropriate matrix depending upon whether the state is (1) comprehensive, or (2) pre-planning.
- 2. Based on the knowledge gained about the state from background literature and from the initial contacts, place checks in the cells to indicate the best sources of information for each question. This approach recognizes the fact that there is variation in the organizational structure and the roles and responsibilities of staff in each state. Questions appropriate to one type of staff member in one state may be more appropriate for a different type of staff member in another state. Not all questions need to be checked since not all questions will be applicable to all states (e.g., some states won't have a coalition yet).
- 3. Use the completed questions by data source matrix to customize interview guides for each data source for each state. Just enter each question checked. If the instrument is too long, revisit step 1. The decision about how to reduce the length of instruments will need to be made by looking at the matrix in Step 1 and making some hard decisions about triage given the number of people who are being asked each question. The practical consequence of not doing this is that you will find yourself in a situation where the last questions on the instrument are given a cursory once-over. These are seldom the least important questions.
- 4. Practice using at least one interview guide with your team partner before you get into an interview situation. If it doesn't work, fix it beforehand along with similar problems in the other interview guides.

#### 1.1.13 **Group Discussion Guide**

A group discussion guide will also be prepared in advance for each state. A group discussion will be conducted in each state for the purpose of finding out which logistic, political and economic barriers must be addressed in moving towards comprehensive cancer planning. The group discussion guide will have the following elements:

• A definition of comprehensive cancer planning should be provided to make sure that we are all talking about the same thing:

"an integrated and coordinated approach to reduce the incidence, morbidity, and mortality [of cancer] through prevention, early detection, treatment, rehabilitation, and palliation."

Be firm in asking group discussion participants to accept this (CDC) definition for the purpose of the group discussion. We are not interested in engaging in a discussion of the proper definition of comprehensive cancer planning.

• One clear, well-defined question should form the basis for the group discussion. Everything else should be used to probe further. The suggested question is:

What are the challenges and barriers affecting comprehensive planning and program implementation and how have they been (can they be) addressed?

However, if this question makes no sense in an individual state, each team can craft its own as long as the essential question remains the same. Just don't leave without an understanding of what the barriers are, how they can be/were dealt with, and what will be needed to make comprehensive cancer planning easier given these barriers.

#### F. What to Take

- The Field Procedures document.
- Interview packets. Each packet contains a customized interview instrument, a brochure, two consent forms, and a face sheet. One packet should be prepared for each interview. For the group discussion(s), make sure that **Group Discussion Face Sheets**, multiple brochures, and consent forms for each participant are included.
- Business cards. A supply of business cards that can be given to participants at the start of each interview.
- Interview schedule. Include phone number and directions.
- Tape recorder, cassette tapes, batteries. Each team member should bring his or her own tape recorder, extra batteries, and enough tapes for all anticipated interviews.
- Fed ex envelope for documents (optional). If you have received most of the supporting documents you expect to get prior to heading into the field, this may not be needed. However, if you anticipate coming back loaded, your back may thank you for bringing a self-addressed fed ex envelope.
- Airline ticket.
- Document summary forms. A dozen or so per team.
- Blank notepads and writing implements for taking interview notes.

#### **II. Field Procedures**

This section covers (1) interview guidelines, (2) group discussion guidelines, (3) data management in the field, and (4) responding to emergent issues in the field.

#### A. Interview Guidelines

Each two-person field team will be responsible for conducting all interviews. The two members of each field team will alternate between the role of interviewer and the role of note taker. All interviews will be audio taped, if this is acceptable to the interviewees. Interviewees will be assured that interviews and group discussion proceedings are confidential, that they will be neither quoted nor attributed, nor will tapes be made available to anyone outside of the project staff. However, interviewees will not be pressured if they are unwilling to be taped. Regardless of taping, notes will be taken by one member of the site visit team on all interviews. Under no condition will a tape be the only record of an interview. Tapes may be unintelligible, lost, or damaged, resulting in loss of data.

<u>Role of interviewer</u>: (Primary responsibilities: Make introductions, conduct interview, conclude interview)

- Introduce the field team to the study participant/interviewee.
- Explain the purpose of the interview. Leave hand-out and business cards and request a business card from each interviewee if it seems appropriate.
- Clarify duration of interview. Adjust as necessary to accommodate time restrictions study participants may have.
- Explain confidentiality measures and the consent form. *Request that the participant read* and sign a consent form. Leave the second copy with them for their records.
- Ask questions in the interview instrument and probe as necessary.
- The interviewer should ask the note taker if he or she has any further questions or if there is anything the interviewee has said that needs to be clarified.
- Once any additional questions are asked and points are clarified, conclude the interview by thanking the interviewee for participating.
- Ask participants if they are interested in reviewing and commenting on the site visit draft

report before it is sent to CDC. Mark their interest on the face sheet. Verify that the contact information on the face sheet is correct.

#### 1.1.13.1.1 Role of note taker: (Primary responsibilities: Take notes, tape record interview)

- Primary responsibility is to make handwritten notes of the conversation that occurs between the interviewer and the study participant/interviewee. Notes will be taken on a separate notepad. The instruments will not have sufficient space for detailed notes.
- Record start and end times of the group discussion in notes.
- Start the tape recorder *after* study participant has agreed to the interview being recorded *and signed the consent form*. Record date, time and interview team at start of tape (can be done in advance). Do not include the name of the interviewer on the tape but ID is OK.
- Continue to monitor the tape recorder to ensure that it is operating correctly, i.e., that it is actually recording; that the tape is turned over when it reaches the end of the first side; and that the tape recorder has not stopped due to dead batteries.
- Stop the tape recorder when the interview is completed.
- Follow up on interviewee responses that require clarification or need further probing. This can be done during the course of the interview (especially when the interviewer has not done this to the necessary extent), or at the end of the interview.
- Note any deviations from the protocol directly onto the notes. This will become an important part of the data collection record.
- Record necessary or missing information on the **Group Discussion Face Sheet**, including: (a) total number of participants, (b) start and end times of the interview, (c) whether scheduled participants actually attended group discussion, and (d) any memos for individual participants or for the discussion as a whole.

# **B.** Group Discussion Guidelines

As described previously, the goal of the group discussion is to find out what logistic, political and economic barriers must be addressed in moving towards comprehensive cancer planning.

<u>Role of moderator</u>: (Primary responsibilities: Make introductions, conduct group discussion, conclude group discussion, thank participants)

• Introduce the field team to the group discussion participants.

- Explain the purpose and duration of the group discussion. *Leave brochure and business cards*.
- Explain confidentiality measures and the consent form. *Request that all participants read and sign consent forms.* Provide participants with a copy for their records.
- Provide participants with a definition of comprehensive cancer planning as defined in the group discussion instrument (described previously).
- Ask the central question in the group discussion instrument and probe as necessary to
  fully understand the barriers, how they have been (can be) handled, and what would
  support the process.
- Guide the discussion to include all participants.
- 1.1.13.1.2 <u>Role of note taker:</u> (Primary responsibilities: Take notes, tape record group discussion)
- Primary responsibility is to make handwritten notes of the conversation that occurs between the interviewer and the group discussion participants. Notes will be taken on a separate notepad. The instruments will not have sufficient space for detailed notes. Link statements to individuals by ID wherever possible.
- Record the start and stop times of the group discussion.
- Start the tape recorder *after* participants have *signed consent forms*. Record date, time and interview team at start of tape (can be done in advance).
- Continue to monitor the tape recorder to ensure that it is operating correctly, i.e., that it is actually recording; that the tape is turned over when it reaches the end of the first side; and that the tape recorder has not stopped due to dead batteries.
- Stop the tape recorder when the interview is completed.

# C. Data Management in the Field

<u>Face sheets</u> (Appendix E) — A face sheet will have been prepared for all participants scheduled for interviews either individually or in the group discussion prior to the site visit. During the site visit, the information should be updated and corrected as needed by hand directly on the sheet. Also note whether the participant wishes to get a copy of the draft case study report for review and comment.

Question tracking form (Appendix G) – The question tracking form, a variation on the matrix of

research/study questions by data source, will be used across all states to keep track of information gained in the field. The tracking form will have the question in the left—hand column with a blank comment field in the right—hand column to write down the source(s) of responses and to briefly summarize what they said. This matrix will be completed in the field and will be checked frequently to assess coverage. The brief summaries will also turn up inconsistencies and contradictions between data sources that can be resolved either in the field or by phone on return. If a study question turns out not to be applicable in this state, this should be noted in the comment field. Please note that this is not a coding exercise. Coding will be done from interviews. It is a simple mechanism to keep our "eye on the ball" in the field.

<u>Document summaries</u> (Appendix H) – Documents collected during the site visit should travel with the person who will be preparing the state summary. For each document obtained during the site visit (and those sent in advance), a document summary form needs to be completed. This may be done by hand or electronically. *This is a good activity to do during any spare time in the field or on long plane trips*. The documents should be sent to John Rose for archiving.

<u>Consent forms</u> (Appendix I) – All signed consent forms should travel back to Arlington with a member of the team based in that office and given to John Rose for safe-keeping.

<u>Interview notes and tapes</u> – Interview notes and tapes should remain with the note taker for that interview. The note taker will be responsible for typing up the notes when they return to the office and then seeking validation and review from the interviewer. Tapes should be labeled for easy identification.

#### **D.** Emergent Issues

As much as we try to plan ahead, unexpected issues always arise in the field. For example, people we wish to interview may be unavailable, new people to interview may surface, or we may discover exciting new planning models. We will all need to be flexible. Be prepared to interview new people and to shift schedules as needed. [Of course, don't forget to update the face sheets to reflect these changes]. Most importantly, remain open to new ideas.

Start a journal or notebook and keep track of what you learn through your informal contacts as well as through the more formal interview process. Be prepared to share this information with the rest of the team.

If issues arrive when in the field that need to be addressed or discussed immediately, **John Rose has graciously agreed to serve as a point of contact**. He can be reached by phone at **703-875-2102** or by email at <a href="mailto:rosej@battelle.org">rosej@battelle.org</a>.

## III. Upon Return

This section covers those activities that need to be completed after returning from the field including (1) thank you letters, (2) data management, (3) data analysis, and (4) report writing.

#### A. Thank You Letters

Each team is responsible for sending thank you letters to everyone interviewed or who otherwise facilitated the visit. Letters should be sent within one week of completion of the site visit. A standard *thank you letter* has been prepared that the team can customize if they wish. Each team may want to designate an official thank you writer for each site. A database with all the names and addresses will be created from the face sheets and used to prepare the thank you letters. An example of a directory of contacts is provided in Appendix J Directory of State Contacts.

#### B. Data Management

<u>Interview notes</u> – Upon return from the field, interviews will by typed into electronic files by the person who acted as note taker. MS Word is the standard software. Notes should begin by identifying the date and time of the interview, the interviewer and note taker, and interview ID. Each question should also be recorded (question number, and actual words used), followed by the answer. The interview notes will then be sent to the interviewer. The interviewer will validate and amplify the electronic record for that interview. Gaps in the data or areas of uncertainty between the two interviewers will be resolved from tapes.

<u>Tapes</u> – Tapes will not be transcribed. They will be used to fill gaps in the notes or to clarify and resolve discrepancies between the notes of the two team members. Each team should hold onto the tapes until the state summary has been written at which time they should be sent to John in Arlington where they will reside until all project deliverables have been completed. The audio tapes will be destroyed once all final project deliverables have been completed.

<u>Completed notes</u> - Send typed, reviewed, and revised notes to John Rose in Arlington (electronically) for input into Nudist. John will coordinate initial coding and indexing of the interview documents for each case study. He will provide the prepared projects to the case study teams for analysis and report write—up.

#### C. Data Analysis

A data analysis plan will be developed in a subsequent round of planning. The code book

will be revised as a result of the development of the data analysis plan. At that time, details of who will perform the analysis activities will be specified.

### **D.** Report Writing

Each team should decide in advance who will prepare the case study report for each state. This will facilitate the process of keeping documents, tapes, and other materials organized and readily accessible to the primary writer. The primary writer will prepare a draft summary and send it to the other team member for review and comment. The primary writer will incorporate comments received and send a hardcopy to Mary Odell Butler for review. After Dr. Butler has cleared the report for distribution, a copy will be sent to the state director and other staff in the state who have indicated an interest for review and comment before the draft report is revised and sent to CDC. The Battelle team for that state is responsible for sending the draft reports out to interested reviewers.

State staff will be given approximately 2 weeks to review the draft. Follow-up calls will be made to secure comments from the state director (but not the other staff) if none have been received by this time.

The primary writer will then revise the report, in consultation with the other team member, based on comments received. Any difficult comments will be addressed through consultation with Dr. Butler. Once the report has been revised, a hardcopy and electronic copy will be sent to Joanne Abed in Arlington for final report preparation. All final summaries provided to the states and to CDC will be sent out from Arlington.

#### Report Outline

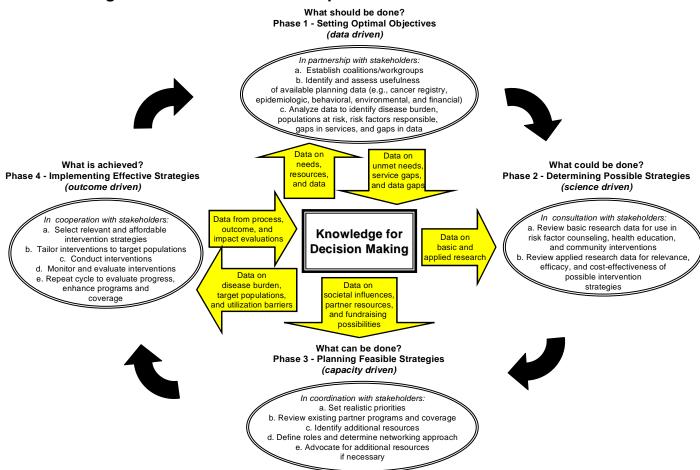
A case study report outline is included as Appendix K.

#### Style Sheet and Language Standardization Guideline

A style sheet and language standardization guideline will be prepared and distributed before writing begins.

### [Protocol] Appendix A: Model

Figure 1. Framework for Comprehensive Cancer Prevention and Control



## [Protocol] Appendix B: Matrix of Research and Study Questions by Data Source

## **Comprehensive States**

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
RQ I. (Structure and Context)										
A. What programs exist within the SHA that deal with cancer from a site-specific, risk factor specific, surveillance, or comprehensive point of view?										
B. How did the heads of these programs and their staff interact during the comprehensive cancer planning process? Could any changes in organization be attributed to the comprehensive cancer planning process?										
C. Could any changes in the manner in which data are kept and used for specific programs or across programs be attributed to the comprehensive cancer planning process?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
D. Could any changes in the interactions between coalition members (i.e., planning and program partners) be attributed to the comprehensive cancer planning process?										
E. What has been the impact of funding streams on efforts to work with people outside of specific programs? Have there been any changes in funding, or the way funds are used, that can be attributed to the comprehensive planning process?										
RQ II. Objective–Setting (Phase I of Working Model)										
A. What steps or activities led to the setting of objectives?										
B. Who was involved in which objective-setting activities and how were relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										
C. How were the objective-setting activities conducted?										

	Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
D.	What were the outcomes of the objective-setting activities?										
E.	When did objective–setting activities take place relative to other activities and how long did they take to accomplish?										
F.	What are the barriers and facilitators relevant to the objective setting process?										
G.	What lessons have been learned about setting cancer control objectives related to undertaking a comprehensive approach?										
pro	III. Identifying/Reviewing gram components (Phase II of rking Model)										
A.	What steps or activities led to the identification of potentially relevant and effective program components?										
В.	Who was involved in which intervention-review activities and how were relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										

	Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
C.	How were the intervention- review activities conducted?										
D.	What were the outcomes of the intervention-review activities?										
E.	When did intervention identification and review activities take place relative to other planning activities and how long did this take to accomplish?										
F.	What are the barriers and facilitators relevant to the identification and review of potential program components?										
G.	What lessons have been learned about identifying and reviewing potential program components related to undertaking a comprehensive approach?										
	IV. Setting priorities (Phase III Working Model)										
A.	What steps or activities have led to the setting of priorities among the many tasks that should/could be undertaken?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
B. Who was involved in whi priority-setting activities a were relationships among stakeholders structured? (for inclusion of minority, underserved, and survivor/advocacy groups	Probe									
C. How were the priority-set activities conducted?	ting									
D. What were the outcomes priority-setting activities?										
E. When did priority-setting activities take place relati other planning activities a long did they take to acco	ve to and how									
F. What are the barriers and facilitators relevant to the of program priorities?	setting									
G. What lessons have been lead out the setting of programmer priorities related to under comprehensive approach?	am taking a									
RQ V. Implementation of procomponents (Phase IV of Workshood)										

	Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
A.	What steps or activities led to the implementation of cancer prevention and control program components?										
В.	Who was involved in which implementation activities and how were relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										
C.	How were the implementation activities conducted?										
D.	What were the outcomes of the implementation activities?										
E.	When have implementation activities taken place relative to other activities and how long do they take to accomplish?										
F.	What are the barriers and facilitators relevant to program component implementation?										
G.	What lessons have been learned about program component implementation related to undertaking a comprehensive approach?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
RQ VI. Feedback (Whole Working Model)										
A. In reviewing the lessons learned? answers to the above research questions, is there evidence of feedback of lessons learned from the prior cancer control activities into the current ones? If so, what were the lessons learned and how and when did the feedback occur?										
B. Do staff think the planning and program implementation process has improved over time?										
C. How many times has the SHA been through a cancer planning process?										
RQ VII. Data (Whole Working Model)										
A. What types of data have been used in the whole planning process?										
<b>B.</b> How did the SHA and its partners identify, analyze and apply data to setting objectives, identifying program components, and setting priorities?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
C. What are the barriers/facilitators and lessons learned from all phases relating specifically to data mobilization, utilization, and development?										
D. In reviewing the What steps? answers to the above research questions, does it appear that data has been mobilized effectively in all, several, or none of the four phases?										
RQ VIII. Partnerships (Whole Working Model)										
A. In reviewing the who? and how? answers to the above research questions, is there evidence of an effort to bring into the planning and implementation process important stakeholders from the health department, other state and local agencies, and the private sector (e.g. voluntary organizations, providers, patient/survivor advocacy groups, minority and underserved populations, and health education professionals)?										

	Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
В.	Have stakeholder commitments and linkages established during the planning phases been maintained and or strengthened as the initiative has moved on to implementation? Why or why not?										
C.	What are the barriers/facilitators and lessons learned from all planning and implementation phases relating specifically to partnership mobilization, utilization, and development?										
RQ Qu	IX. Barriers (Focus Group ex)										
A.	What are the barriers within the state health agency that affect planning and program implementation?										
В.	What are the barriers outside of the state health agency that affect planning and program implementation?										
C.	How are the barriers addressed or overcome?										
D.	What kinds of support or assistance are needed to undertake a comprehensive approach to cancer control?										

# [Protocol] Appendix B: Matrix of Research & Study Questions by Data Source

### **Pre-planning States**

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
RQ I. (Structure and Context)										
A. What programs exist within the SHA that deal with cancer from a site-specific, risk factor specific, surveillance, or comprehensive point of view?										
B. How do the heads of these										
C. Who might staff and coalition heads need to work with in undertaking a comprehensive planning approach that they have not worked with in the past?  (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										
D. What has been the impact of funding streams on efforts to work with people outside of specific programs?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
E. What concerns do respondents express regarding the impact of comprehensive cancer planning on the present organizational structure of cancer-related programs in the SHA and the other agencies or coalitions with which they interact?										
RQ II. Objective–Setting (Phase I of Working Model)										
A. What steps or activities lead to the setting of cancer control objectives?										
B. Who is involved in objective- setting activities and how are the relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										
C. How are the objective-setting activities conducted?										
D. What have been the outcomes of objective-setting activities?										
E. When do objective–setting activities take place relative to other activities and how long do they take to accomplish?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
F. What are the barriers and facilitators relevant to the objective setting process?										
G. What lessons have been learned about setting cancer control objectives that apply to undertaking a comprehensive approach?										
RQ III. Identifying/Reviewing program components (Phase II of Working Model)										
A. What steps or activities lead to the identification of potentially relevant and effective program components?										
B. Who is involved in intervention identification and review activities and how are relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										
C. How are intervention identification and review activities conducted?										

	Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
D.	What are the outcomes of intervention identification and review activities?										
E.	When do intervention identification and review activities take place relative to other planning activities and how long does this take to accomplish?										
F.	What are the barriers and facilitators relevant to the identification and review of potential program components?										
G.	What lessons have been learned about identifying and reviewing potential program components that apply to undertaking a comprehensive approach?										
	IV. Setting priorities (Phase III Working Model)										
A.	What steps or activities lead to the setting of priorities among the many tasks that should/could be undertaken?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
B. Who is involved in priority- setting activities and how are relationships with the stakeholders structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										
C. How are the priority-setting activities conducted?										
D. What are the outcomes of priority-setting activities?										
E. When do priority-setting activities take place relative to other planning activities and how long do they take to accomplish?										
F. What are the barriers and facilitators relevant to the setting of program priorities?										
G. What lessons have been learned about the setting of program priorities that apply to undertaking a comprehensive approach?										
RQ V. Implementation of program components (Phase IV of Working Model)										

	Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
A.	What steps or activities lead to the implementation of cancer prevention and control program components?										
В.	Who is involved in which implementation activities and how are relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)										
C.	How are the implementation activities conducted?										
D.	What are the outcomes of the implementation activities?										
E.	When do implementation activities take place relative to other activities and how long do they take to accomplish?										
F.	What are the barriers and facilitators relevant to program implementation?										
G.	What lessons have been learned about program implementation that apply to undertaking a comprehensive approach?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
RQ VI. Feedback (Whole Working Model)										
A. In reviewing the lessons learned? answers to the above research questions, is there evidence of feedback of lessons learned from the prior cancer control activities into the current ones? If so, what were the lessons learned and how and when did the feedback occur?  B. Do staff feel that their cancer control efforts have improved over time?										
RQ VII. Data (Whole Working Model)										
A. What types of data are used in cancer control planning?										
B. How do the SHA and its partners identify, analyze and apply data to setting objectives, identifying program components, and setting priorities?										
C. What are the barriers/facilitators and lessons learned relating specifically to data mobilization, utilization, and development?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
D. In reviewing the What steps? answers to the above research questions, does it appear that data is being mobilized effectively in all, several, or none of the four phases?										
RQ VIII. Partnerships (Whole Working Model)										
A. In reviewing the who? and how? answers to the above research questions, is there evidence of an effort to bring into the planning and implementation process important stakeholders from the health department, other state and local agencies, and the private sector (e.g. voluntary organizations, providers, patient/survivor advocacy groups, minority and underserved populations, and health education professionals)?										
B. Have stakeholder commitments and linkages been maintained and/or strengthened over the lifespan of specific planning and implementation efforts and beyond? Why or why not?										

Research/Study Question	Study Question not applicable to state	State Program Director	State/local HD program staff	Data management– surveillance staff	Coalition leader	Coalition member	State legislator or staff person	Rep. from community organizations	Focus Group	Documents
C. What are the barriers/facilitators and lessons learned from all planning and implementation activities relating specifically to partnership mobilization, utilization, and development?										
RQ IX. Barriers										
A. What are the barriers within the state health agency that will affect planning and program implementation?										
B. What are the barriers outside of the state health agency that will affect planning and program implementation?										
C. How could the barriers be addressed or overcome?										
D. What kinds of support or assistance are needed to undertake a comprehensive approach to cancer control?										

## [Protocol] Appendix C: Recommended Reading

## **CDC Internal Documents**

ID#	Authors	Brief Description
26	Kean et al.	Summary of conference calls with 190 chronic disease directors and other cancer control stakeholders in 45 states and 2 territories.  Prepared by Strategic health Concepts, Inc., for CDC, August 14, 1995. First appearance of the four-part model.
34	Kean et al.	Executive summary and meeting minutes from a conference sponsored by CDC entitled "Toward a Comprehensive Public Health Approach to Cancer Prevention and Control" and held in Atlanta in May 1996. About 65 attendees from a wide range of stakeholder groups.
36	Kean et al.	Summary of comprehensive cancer control workgroup meeting held in Denver on October 30, 1996, facilitated by Strategic Health Concepts, Inc., for CDC. Battelle's first attendance at one of DCPC's comprehensive cancer control meetings.
50	Kean et al.	Summary of state cancer plans solicited and analyzed by Strategic Health Concepts, Inc. The purpose of SHC's analysis was to examine whether and (if so) how states are fostering comprehensive and integrated cancer programs. Although it was difficult to determine from the available plans, SHC concluded that there was little evidence of comprehensive planning and programming in most state plans.

### **Published Articles**

ID#	Authors	Brief Description
10	Alciati and Marconi	Description of the historical role of SHAs in public health action.
		Authors argue that the traditional role can be translated into state-
		level cancer prevention and control efforts.
14	Lillquist et al.	Role of data in cancer planning by New York, a DBIR state.
22	Alciati and Glanz	Description of the use of data in cancer prevention and control
		planning in five DBIR states: GA, MD, ND, VT, and WA.
		Conclusions are drawn from the five cases about strengths and
		weaknesses of the data-based planning process.
37	Boss and Suarez	Overview of how various types of data can be used in state-level
		cancer planning. Based on the DBIR experience in IL, NE, NJ,
		NY, NC, TX, and WI.
43	Alciati	Overview of the history of data-based state-level cancer planning,
		stressing the infrastructure development that had to be done
		before it could be implemented on even a limited scale for DBIR.
49	Brownson and Bal.	General plan for SHAs to assist in translating cancer control research
		into community-level interventions. Ten future priorities are
		proposed to guide SHA efforts.
52	Goodman et al.	Process evaluation of NCI's DBIR program.
53	Steckler et al.	Impact evaluation of NCI's DBIR program.

[Protocol] Appendix D: Brochure

[Protocol] Appendix E: Face Sheet

## [Protocol] Appendix F: Daily Schedule Form

State:	Dates:
State:	Butcs:

Time	Arrival:	First Day:	Second Day:	Third Day:	Departure:
7:00 am				,	
7:30					
9:30					
10:00					
10:30					
11:00					
11:30					
12:00					
Noon					
12:30					
1:00					
1:30					
2:00					
2:30					
3:00					

Time	Arrival:	First Day:	Second Day:	Third Day:	Departure:
3:30					
4:00					
4:30					
5:00					
5:30					
6:00					
6:30					

## [Protocol] Appendix G: Research and Study Question Tracking Sheet

## **Comprehensive States**

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
RQ I. (Structure and Context)	
A. What programs exist within the SHA that deal with cancer from a site-specific, risk factor specific, surveillance, or comprehensive point of view?	
B. How did the heads of these programs and their staff interact during the comprehensive cancer planning process? Could any changes in organization be attributed to the comprehensive cancer planning process?	
C. Could any changes in the manner in which data are kept and used for specific programs or across programs be attributed to the comprehensive cancer planning process?	

	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
D.	Could any changes in the interactions between coalition members (i.e., planning and program partners) be attributed to the comprehensive cancer planning process?	
E.	What has been the impact of funding streams on efforts to work with people outside of specific programs? Have there been any changes in funding, or the way funds are used, that can be attributed to the comprehensive planning process?	
	II. Objective–Setting (Phase I of rking Model)	
A.	What steps or activities led to the setting of objectives?	
В.	Who was involved in which objective- setting activities and how were relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
C.	How were the objective-setting activities conducted?	

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
D. What were the outcomes of the objective-setting activities?	
E. When did objective–setting actake place relative to other act and how long did they take to accomplish?	
F. What are the barriers and faci relevant to the objective settin process?	
G. What lessons have been learn setting cancer control objective related to undertaking a comprehensive approach?	
RQ III. Identifying/Reviewing promponents (Phase II of Workin Model)	
A. What steps or activities led to identification of potentially re and effective program compo	evant

	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
В.	Who was involved in which intervention-review activities and how were relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy	The there surprises, panerus, or theorisistences.
C.	groups.)  How were the intervention-review activities conducted?	
D.	What were the outcomes of the intervention-review activities?	
E.	When did intervention identification and review activities take place relative to other planning activities and how long did this take to accomplish?	
F.	What are the barriers and facilitators relevant to the identification and review of potential program components?	
G.	What lessons have been learned about identifying and reviewing potential program components related to undertaking a comprehensive approach?	

Pool	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
	IV. Setting priorities (Phase III of orking Model)	
A.	What steps or activities have led to the setting of priorities among the many tasks that should/could be undertaken?	
В.	Who was involved in which priority- setting activities and how were relationships among stakeholders structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
C.	How were the priority-setting activities conducted?	
D.	What were the outcomes of the priority-setting activities?	
E.	When did priority-setting activities take place relative to other planning activities and how long did they take to accomplish?	
F.	What are the barriers and facilitators relevant to the setting of program priorities?	

	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
G.	What lessons have been learned about the setting of program priorities related to undertaking a comprehensive approach?	
con	V. Implementation of program apponents (Phase IV of Working del)	
A.	What steps or activities led to the implementation of cancer prevention and control program components?	
В.	Who was involved in which implementation activities and how were relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
C.	How were the implementation activities conducted?	
D.	What were the outcomes of the implementation activities?	
E.	When have implementation activities taken place relative to other activities and how long do they take to accomplish?	

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
F. What are the barriers and facilitators relevant to program component implementation?	
G. What lessons have been learned about program component implementation related to undertaking a comprehensive approach?	
RQ VI. Feedback (Whole Working Model)	
A. In reviewing the lessons learned? answers to the above research questions, is there evidence of feedback of lessons learned from the prior cancer control activities into the current ones? If so, what were the lessons learned and how and when did the feedback occur?	
B. Do staff think the planning and program implementation process has improved over time?	
C. How many times has the SHA been through a cancer planning process?	
RQ VII. Data (Whole Working Model)	

	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
	What types of data have been used in the whole planning process?	
	How did the SHA and its partners identify, analyze and apply data to setting objectives, identifying program components, and setting priorities?	
	What are the barriers/facilitators and lessons learned from all phases relating specifically to data mobilization, utilization, and development?	
	In reviewing the What steps? answers to the above research questions, does it appear that data has been mobilized effectively in all, several, or none of the four phases?	
RQ Mod	VIII. Partnerships (Whole Working lel)	

		Data Source Inventory and Comments
	Research/Study Question	Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
	In reviewing the who? and how? answers to the above research questions, is there evidence of an effort to bring into the planning and implementation process important stakeholders from the health department, other state and local agencies, and the private sector (e.g. voluntary organizations, providers, patient/survivor advocacy groups, minority and underserved populations, and health education professionals)?  Have stakeholder commitments and linkages established during the	
C.	planning phases been maintained and or strengthened as the initiative has moved on to implementation? Why or why not?  What are the barriers/facilitators and lessons learned from all planning and	
RQ	implementation phases relating specifically to partnership mobilization, utilization, and development?  IX. Barriers (Focus Group Quex)	

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?	
A. What are the barriers within health agency that affect plan program implementation?		
B. What are the barriers outside state health agency that affect planning and program implementation?	he	
C. What kinds of support or ass are needed to undertake a comprehensive approach to control?		

# <u>Pre-planning States</u>

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
A. What programs exist within the SHA that deal with cancer from a site-specific, risk factor specific, surveillance, or comprehensive point of view?	
B. How do the heads of these programs and their staff interact with each other?	
C. Who might staff and coalition heads need to work with in undertaking a comprehensive planning approach that they have not worked with in the past? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
D. What has been the impact of funding streams on efforts to work with people outside of specific programs?	

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
E. What concerns do respondents express regarding the impact of comprehensive cancer planning on the present organizational structure of cancer-related programs in the SHA and the other agencies or coalitions with which they interact?	
RQ II. Objective–Setting (Phase I of Working Model)	
A. What steps or activities lead to the setting of cancer control objectives?	
B. Who is involved in objective-setting activities and how are the relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
C. How are the objective-setting activities conducted?	
D. What have been the outcomes of objective-setting activities?	
E. When do objective–setting activities take place relative to other activities and how long do they take to accomplish?	

	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
F.	What are the barriers and facilitators relevant to the objective setting process?	
G.	What lessons have been learned about setting cancer control objectives that apply to undertaking a comprehensive approach?	
	III. Identifying/Reviewing program components (interventions) (Phase II of Working Model)	
A.	What steps or activities lead to the identification of potentially relevant and effective program components (interventions)?	
В.	Who is involved in intervention identification and review activities and how are relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
C.	How are intervention identification and review activities conducted?	
D.	What are the outcomes of intervention identification and review activities?	

	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
E.	When do intervention identification and review activities take place relative to other planning activities and how long does this take to accomplish?	
F.	What are the barriers and facilitators relevant to the identification and review of potential program components?	
G.	What lessons have been learned about identifying and reviewing potential program components that apply to undertaking a comprehensive approach?	
	IV. Setting priorities (Phase III of orking Model)	
	What steps or activities lead to the setting of realistic priorities among the many tasks that should/could be undertaken?	

	Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
В.	Who is involved in priority-setting activities and how are relationships with the stakeholders structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
C.	How are the priority-setting activities conducted?	
D.	What are the outcomes of priority-setting activities?	
E.	When do priority-setting activities take place relative to other planning activities and how long do they take to accomplish?	
F.	What are the barriers and facilitators relevant to the setting of program priorities?	
G.	What lessons have been learned about the setting of program priorities that apply to undertaking a comprehensive approach?	
con	V. Implementation of program ponents (interventions) (Phase IV of rking Model)	

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
A. What steps or activities lead to the implementation of cancer prevention and control programs?	
B. Who is involved in which implementation activities and how are relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.)	
C. How are the implementation activities conducted?	
D. What are the outcomes of the implementation activities?	
E. When do implementation activities take place relative to other activities and how long do they take to accomplish?	
F. What are the barriers and facilitators relevant to program implementation?	
G. What lessons have been learned about program implementation that apply to undertaking a comprehensive approach?	
RQ VI. Feedback (Whole Working Model)	

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
A. In reviewing the lessons learned? answers to the above research questions, is there evidence of feedback of lessons learned from the prior cancer control activities into the current ones? If so, what were the lessons learned and how and when did the feedback occur?	
B.Do staff feel that their cancer control efforts have improved over time?  RQ VII. Data (Whole Working Model)	
A.What types of data are used in cancer control planning?	
B.How do the SHA and its partners identify, analyze and apply data to setting objectives, identifying program components, and setting priorities?	
C. What are the barriers/facilitators and lessons learned relating specifically to data mobilization, utilization, and development?	

D. In reviewing the What steps? answers to the above research questions, does	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
it appear that data is being mobilized effectively in all, several, or none of the four phases?  RQ VIII. Partnerships (Whole Working Model)	
A. In reviewing the who? and how? answers to the above research questions, is there evidence of an effort to bring into the planning and implementation process important stakeholders from the health department, other state and local agencies, and the private sector (e.g. voluntary organizations, providers, patient/survivor advocacy groups, minority and underserved populations, and health education professionals)?	
B. Have stakeholder commitments and linkages been maintained and/or strengthened over the lifespan of specific planning and implementation efforts and beyond? Why or why not?	

Research/Study Question	Data Source Inventory and Comments  Who has addressed the question?  Are there surprises, patterns, or inconsistencies?
C. What are the barriers/facilitators and lessons learned from all planning and implementation activities relating specifically to partnership mobilization, utilization, and development?	
RQ IX. Barriers	
A. What are the barriers within the state health agency that will affect planning and program implementation?	
B. What are the barriers outside of the state health agency that will affect planning and program implementation?	
C. What kinds of support or assistance are needed to undertake a comprehensive approach to cancer control?	

# [Protocol] Appendix H: Document Summary Form

# **Appendix I: Consent Forms**

# Essential Elements for Developing/Expanding Comprehensive Cancer Control Programs: Design Options for State Health Agencies

#### **Informed Consent Form**

Interview

Battelle is an independent research organization doing this study under a contract with the US Centers for Disease Control and Prevention. The purpose of this study is to understand factors affecting planning for the prevention and control of cancer in your state and to help CDC develop a guidance document for all states to use in undertaking comprehensive cancer planning. Your state is one of several that has been asked to participate in this study. We are speaking to health department staff, members of community organizations, health care providers, and other officials to understand the context and the process of planning in this state. The information that you and other study participants give us will be assembled to write the reports for the project and to develop CDC guidance for other states to use in their own planning processes.

Your participation in this study is voluntary. We will keep this interview confidential and will not quote you by name or attribute any statements to you. Your name will not appear in any reports or documents. If at any time during this interview you want to stop, please say so and we will conclude the interview. We expect this interview to take between 30 minutes to one hour to complete.

In order to ensure an accurate record, we would like to make an audio tape recording of this interview. The tape recording will only be used by members of the Battelle research team to verify information covered during the interview if necessary. All tape recordings are destroyed at the end of the project.

Do you agree to a	allow us to tape record	the interview?	
Yes			
No			
	•	f you have been informed of and s for this study, and agree to partic	
Name (pl	ease print):		
Signature	:	Date:	
		Case ID#	

If you have any questions regarding the study and our measures to protect study participant confidentiality, please contact Dr. Mary Odell Butler (703) 875–2966, or John M. Rose (703) 875–2102.

If you have any questions about your rights as a research participant, contact Dr. Margaret Pennybacker at (919) 544–3717.

# Essential Elements for Developing/Expanding Comprehensive Cancer Control Programs: Design Options for State Health Agencies

#### **Informed Consent Form**

**Group Discussion** 

Battelle is a research organization doing this study under a contract with the US Centers for Disease Control and Prevention. The purpose of this study is to understand factors affecting planning for the prevention and control of cancer in your state and to help CDC develop a guidance document for all states to use in undertaking comprehensive cancer planning. Your state is one of several that has been asked to participate in this study. We are convening meetings like this to capture the understanding and perceptions of people about cancer planning and programming in their states. The results of these meetings will be used to support our development of CDC guidance for other states in their own planning processes.

We will be audio tape recording the meeting. However, we will keep the proceedings of this meeting confidential and will not disseminate the proceedings to anyone who is not in this room now. We will not quote you by name or attribute any statements to you. Nor will your name appear in any reports or documents.

Your participation in this group is voluntary. You may leave at any time. We expect this group to take about two hours to complete.

Please print your name and sign below if you have been informed of and understand the above statements on confidentiality procedures for this study.

Name (please print):	
Signature:	Date:
	Group Discussion ID#

If you have any questions regarding the study and our measures to protect study participant confidentiality, please contact Dr. Mary Odell Butler (703) 875–2966, or John M. Rose (703) 875–2102.

If you have any questions about your rights as a research participant, contact Dr. Margaret Pennybacker at (919) 544–3717.

# [Protocol] Appendix J. Contact Information

First Name	Last Name	Title/position	Program	Telephone	Extension	Fax	Email

# [Protocol] Appendix K: Case Study Report Outline

# 1.1.13.2 I. Case Study Approach in the State

## A. Study Purpose

Can be repeated verbatim in all 6 reports. Include guiding framework (Model).

#### **B**. Data Collection

State when the site visit occurred, the individuals comprising the site visit team, and the number and types of people interviewed. Also briefly describe other data or documents collected.

# C. Data Coding and Analysis

Can be repeated verbatim in all 6 reports. Describe process for typing notes, text processing software used, and any other analytic techniques used.

#### **D.** Special Methodological Considerations

Describe any conditions that had an effect on methods or non-standard procedures.

# II. Findings

#### A. Background of the State Cancer Planning Process

Describe the history of the planning process to date and where the state currently falls in the process. Also describe the context in which planning is occurring, drawing on the data provided in John Rose's site selection document and the state profile.

#### 1.1.14 B. Planning Structure

Explicitly describe the structure of the planning process in the state.

#### 1.1.15 C. Setting Planning Objectives

Describe the process used by the state to produce a set of planning objectives. Include who was involved (minority, underserved, and survivor populations?), what happened, what data were used, and how the objectives were operationally defined. List objectives.

### 1.1.16 D. Determining Program Components

Describe the range of program components considered, the process used to identify optimal program components, and the outcomes of that process.

#### 1.1.17 E. Linking Programs to Resources

Describe how the elements of the program were prioritized and how resources and roles were identified and defined. Who, what, how.

#### 1.1.18 F. Implementing Programs

Describe any activities that have been implemented and the outcomes of those activities. Include evaluation data, if any, or plans for evaluating programs.

### 1.1.19 G. Feedback into the Planning Process

Use this section to describe whether and how the planning process itself is contributing to an expansion and/or reinforcement of the comprehensive planning process.

#### 1.1.20 H. Role of Data in Planning

Describe the extent to which data have been used to support comprehensive cancer planning across all steps of the planning process and any difficulties encountered. Describe how the data management and analysis is structured.

#### 1.1.21 I. Role of Partnerships/Coalitions

Describe the role of cancer coalitions or other community or advocacy groups who are acting in partnership with the state health department for the purpose of comprehensive cancer planning. Any insights into why groups are or are not participating, or the value that the site sees in their participation should also be included. Special attention should be devoted the inclusion of minority and underserved populations (see CDC definitions for these groups), as well as cancer survivor groups. Future plans are also of interest.

#### 1.1.22 J. Other Information

Use this section to provide information on other important findings that do not fit under the headings above. Include here extent to which other planning models are evident and describe those models.

# **Conclusions**

# 1.1.23 A. Barriers and Facilitators to Comprehensive Planning

Summarize the difficulties and successes encountered in trying to implement a comprehensive planning process. Describe the level of effort and time involved.

#### 1.1.24 B. Recommendations

Use this section to summarize the advice to others provided by respondents in the individual interviews and the recommendations from the focus group on the challenges to the planning process and strategies they have developed for coping with those challenges. Also summarize respondents' input into the kind of help they would find useful.

# [Protocol] Appendix L: Identification Number System

For the Cancer Task 1 multiple—case study project, we will use an identification number system specifying an ID for each of the data sources described in the protocol and the case study field guide, e.g., individual interviews, group discussion interviews, and supporting documents.

Below is an ID summary table for each type of data source. Following the summary table is a detailed description of each type of ID.

**Table 1: Summary of Identification Number System** 

Data Source	Example of	Components of ID		
Study participant (ID#)	ID 34pd01	State ID  04 = Arkansas  14 = Illinois  20 = Maine  23 = Michigan  34 = North Carolina  45 = Utah	Participant Category pd= State Program Director ps= State/local health department program staff dm= Data management staff cl= Coalition leader cm= Coalition member sl= State legislator or staff person co= Community/advocacy organization leader ot= other	Unique Number  Whole number between 01 and 99, begins with 01 for each state
Group Discussion (GD#)	34GD[01]	State ID	"GD" for group discussion	Unique Number (if more than one group discussio n)
Supporting document (DOC#)	34DC01	State ID	"DC" for document	Unique Number

# **Study Participant Identification Number**

The Study Participant Identification Number (ID#) is for all people who participate in a state case study, either as interviewees or as group discussion participants, or both. The ID# is a six character code consisting of three elements in the following order:

- 1. A two-digit state identification number for the participant's state,
- 2. A two-letter abbreviation (lower case) indicating the interviewee type,

3. A number unique (within the participant's state) between 01 and 99.

An example of an ID# is:

Ex.: 34pd01

The table below shows the three elements of the ID and the possible values for each.

State ID	Participant category	Unique number
04 = Arkansas 14 = Illinois 20 = Maine 23 = Michigan 25 = Mississippi 34 = North Carolina 38 = Oregon	pd = State Program Director ps = State/local health department program staff dm = Data management staff cl = Coalition leader cm = Coalition member sl = State legislator or staff person co = Community/advocacy organization leader ot = other  If person does not fit into one of the above categories, use "other" category and discuss with team if a new category is necessary.	Any whole number between 01 and 99.  Numbering begins fresh for each state, rather than numbering through all the states continuously.

The Study Participant ID# serves as the primary field for the Participant Tables in both the project and individual case study databases. The ID# and the three components can be used to identify, sort, and group different classes of study participants during data exploration and analysis.

The ID# also serves as the name for all interview notes. All interview notes, whether hand—written or typed, are labeled only with the ID#'s. When interview notes are typed into the word processor and saved, they will named by ID#. This serves to protect confidentiality and facilitates the linking between documents in the NUDIST project file and the records in the Participant Tables.

The participant ID# can not protect confidentiality entirely. Identity of respondent can be reconstructed partially if the codes of the four elements are known. Therefore, this information about the identification system should not be shared with people who are not Battelle CPHRE staff. Furthermore, ID#'s should not be referred to in documents shared with clients or the public.

# **Group Discussion Identification Number**

The Group Discussion Identification Number (GD#) is a four character code consisting of two elements in the following order:

1. A two-digit state identification number (same as for participant ID#),

#### 2. The letters "GD"

An example of an GD# is:

Ex.: 34GD

The GD# serves as the primary field for the Focus Groups Table in the project and case study databases. The GD# also serves as the name for all group discussion interview note files. All group discussion interview notes, whether hand—written or typed, are labeled only with the GD#'s. When interview notes are typed into the word processor and saved, they should be named by GD#. This serves to protect confidentiality and facilitates the linking between documents in the NUDIST project file and the records in the Focus Group Tables.

Please note that the participants in the group discussions will be named and identified by their Study Participant ID#'s. Again, this protects confidentiality and allows us to group responses by participant from both interviews and group discussions within NUDIST.

# **Supporting Document Identification Number**

The supporting document identification number (DOC#) is a six character code consisting of three elements in the following order:

- 1. A two-digit state identification number indicating the state of origin for the document (same as ID#),
- 2. A two-letter abbreviation (upper case) indicating it is a supporting document, and
- 3. A number unique (within the associated state) between 01 and 99.

An example of an DOC# is:

Ex.: 34DC01

The DOC# serves as the primary field for the Document Tables in both the project and individual case study databases. The DOC# also serves as the name for all document summaries. All document summaries are labeled with the DOC#'s, and when they are typed into the word processor and saved, they will named by DOC#. This facilitates data management and the linking between the NUDIST project indexing systems and the records in the Document Tables.

Appendix E Interview Instruments

# Appendix E-1

# **Instruments for Comprehensive States**

# Interview Guide AA–C State Program Director, Chronic Disease Director

# **Comprehensive States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

# **Orientation**

- 1. I would like to learn more about **<u>your position</u>** here. What is your job title and what are your responsibilities?
  - 1.1. Program decision—making authority? (i.e., what will or will not be done)
  - 1.2. Funding authority?
- 2. How did the **health department become involved** in the current comprehensive planning effort?
- 3. Can you briefly **describe your own involvement** in that process?
  - 3.1. When did you become involved in the planning effort?
  - 3.2. How and Why did you become involved?

- 4. Was this **the first time** your state has undertaken a state—wide cancer planning effort? 4.1. If not, how many times before and when? **Objective Setting** 5. Prior to comprehensive planning, how were cancer control objectives developed and defined in your state's planning process? 5.1. Timing? 5.2. People involved and how? 5.3. Role of HD? 5.4. Reps of minority and advocacy groups? 5.5. Consensus/agreement among planners? If so, how? If not, why? 5.6. Needs assessment? 5.7. Resource inventory? 5.8. Data-epidemiological, financial and health care utilization? 5.9. Other results? 6. What were the most **challenging aspects** of defining objectives and why? **Program Components (Interventions)** 7. **Prior to comprehensive planning, how** were program components (interventions) identified?
  - Rep. of minorities/advocacy?

People involved and why?

Role of the HD?

Timing?

7.1.

7.2.

7.3.

7.4.

- 7.5. Was there an effort to <u>compare alternative intervention strategies</u> to identify those most appropriate for the state?
- 7.6. How were potential interventions <u>reviewed for scientific evidence</u> of effectiveness, efficacy and cost effectiveness?
- 7.7. How were potential interventions **evaluated relative to the needs assessment**?
- 7.8. What kinds of interventions were selected for review, and which were ultimately proposed?
- 7.9. **How were they linked** to the objectives?
- 8. What were the most **challenging aspects** of identifying potential program components and why?

## **Priority-Setting**

- 9. Given broad cancer control objectives and the range of possible programs/interventions that could be implemented, <a href="https://www.neer.ealistic.no.nd/">how were realistic</a>
  <a href="programmatic priorities determined">programmatic priorities determined</a>, <a href="priorities determined">prior to the advent of comprehensive</a>
  <a href="planning">planning</a>? In other words, how was it decided what could be done to achieve the objectives in light of the resources available to the health department and its partners?
  - 9.1. Timing?
  - 9.2. People involved and why?
  - 9.3. What factors were taken into consideration when determining programmatic priorities? Why these factors?
  - 9.4. What were <u>the results of the priority-setting process</u> and <u>why</u> were the selected programmatic priorities settled upon?
- 10. What were the most **challenging aspects** of setting program priorities and why?

## **Implementation**

- 11. Prior to the comprehensive planning process, what **kinds of programs were implemented**?
  - 11.1. Timing
  - 11.2. Any site-specific or risk-factor specific programs that have been implemented **across categorical programs** (e.g. cross-referral, exchange of informational materials, etc.)?
  - 11.3. By whom?
    - 11.3.1. If implementation is carried out by other than SHA, what is the relationship if any at all?
  - 11.4. What <u>resources</u> were brought in <u>by other agencies of state and local</u> <u>government and/or the private sector</u>?
  - 11.5. What productive **linkages** established?
  - 11.6. <u>Were any evaluations done</u> and what have these shown about efficacy, effectiveness and cost effectiveness?
  - 11.7. <u>Were the results of program evaluations used</u> for future planning and program development?
- 12. What were the most **challenging aspects** of program implementation and why?

## **Outcomes of the Planning Process**

- 13. Prior to the comprehensive planning process, what were the interactions among:
  - 13.1. health department staff,
  - 13.2. health department agencies,
  - 13.3. health department and external organizations, or
  - 13.4. external organizations?

- 14. How did the nature and status of cancer funding streams affect efforts to work with organizations or stakeholders in other agencies or outside of the health department?
  - 14.1. Have there been any changes in funding streams, or the way funds are used, that can be attributed to the comprehensive planning process? If so, what happened?
- 15. How did organizational structure affect efforts to work with organizations or stakeholders in other agencies or outside of the health department?
  - 15.1. Have there been any changes in organizational structures or how they function that can be attributed to the comprehensive planning process? If so, what happened?

## **Conclusion**

- 16. Based on your experience, what advice would you give to other States that are beginning a comprehensive planning process?
  - 16.1. What do you wish you had known when you started?
  - 16.2. What kind of help would have been useful to you?

Ask if the Notetaker has anything questions or clarifications.

Ask the Interviewee if they have anything they would like to say or add before we end the interview.

# **Interview Guide AB–C Cancer Planning Managers**

# **Comprehensive States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

#### **Orientation**

- 17. I would like to learn more about **your position** here. What is your job title and what are your responsibilities?
  - 17.1. Program decision—making authority? (i.e., what will or will not be done)
  - 17.2. Funding authority?
- 18. How and why did the <u>health department become involved</u> in the comprehensive planning effort?
- 19. Can you briefly **describe your own involvement** in that process?
  - 19.1. When did you become involved in the planning effort?
  - 19.2. How and Why did you become involved?

- 20. Is this **the first time** your state has undertaken a state—wide cancer planning effort?
  - 20.1. If not, how many times and when?
- 21. What types of **planning bodies**, such as work groups, coalitions, committees have you developed to support the planning process?
  - 21.1. What lessons have you learned in working with these bodies?

State cancer control staff have told us that the four major tasks involved in cancer planning and programming are: (1) setting objectives, (2) selecting program components, (3) determining priorities, and (4) implementing programs. Do these steps make sense to you? Are we missing something? We'd like to ask you some questions about what you have done in each of these steps.

# **Objective Setting**

- 22. <u>How (were/are) cancer control objectives developed</u> and defined in your state's planning process?
  - 22.1. Timing?
  - 22.2. People involved and how?
  - 22.3. Role of HD?
  - 22.4. Reps of minority and advocacy groups?
  - 22.5. Consensus/agreement among planners? If so, how? If not, why?
  - 22.6. Needs assessment?
  - 22.7. Data–epidemiological, financial and health care utilization?
  - 22.8. Other results?
- 23. What are the <u>cancer prevention and control objectives</u> defined in the planning process (if they already have been defined?)
- 24. What are the most **challenging aspects** of defining comprehensive objectives and why?

#### **Program Components (Interventions)**

- 25. <u>How</u> should program components (interventions) to achieve the objectives be **identified**?
  - 25.1. Role of the HD?
  - 25.2. Timing?
  - 25.3. People involved and why?
  - 25.4. Rep. of minorities/advocacy?

- 25.5. Was/is there an effort to <u>compare alternative intervention strategies</u> to identify those most appropriate for the state?
- 25.6. How were/are potential interventions <u>reviewed for scientific evidence</u> of effectiveness, efficacy and cost effectiveness?
- 25.7. How were/are potential interventions **evaluated relative to the needs assessment**?
- 25.8. What kinds were selected for review, and which ones were ultimately proposed?
- 25.9. **How were/are they linked** to the comprehensive planning objectives?
- 26. What are the most **challenging aspects** of identifying potential program components and why?

## **Priority-Setting**

- 27. Given the cancer control objectives and the range of possible programs/interventions that could be implemented, **how should realistic programmatic priorities be determined**? In other words, how should it be decided what can be done to achieve the objectives in light of the resources available to the health department and its partners?
  - 27.1. Timing?
  - 27.2. People involved and why?
  - 27.3. What factors were taken into consideration when determining programmatic priorities? Why these factors?
  - 27.4. What were <u>the results of the priority-setting process</u> and <u>why</u> were the selected programmatic priorities settled upon?
- 28. What are the most **challenging aspects** of setting program priorities and why?

# **Implementation**

- 29. How do you envision the planning process leading to the **implementation of programs** to achieve the objectives?
  - 29.1. Timing
  - 29.2. What kinds of cancer prevention and control activities do you envision that might not (happen/have happened) if this planning process (had never occurred/never occurs)?
  - 29.3. What <u>kinds of site-specific or risk-factor specific programs</u> could be implemented <u>across categorical boundaries</u> as part of a comprehensive planning process (e.g. cross-referral, exchange of informational materials, etc.)?
- 30. Who is responsible for the implementation of intervention programs?
  - 30.1. If implementation is carried out by other than SHA, what is the relationship if any at all?
  - 30.2. What <u>resources (did/can) the health department provide</u> to the program implementations from its own staff and funding?
  - 30.3. What <u>resources</u> (were brought/will be sought) in <u>by other agencies of state</u> and local government and/or the private sector in support of the implemented programs?
  - 30.4. Have <u>linkages</u> established during the previous planning phases been <u>used to support implementations</u>? (Or will they be?)
- 31. How do you envision monitoring **outcomes** that result from program interventions in a way that is <u>linked to</u> the comprehensive planning process?
  - 31.1. <u>Have any evaluations been done</u> and what have these shown about efficacy, effectiveness and cost effectiveness? (Or will they be?)
  - 31.2. Have (Will) <u>the results of program evaluations been (be) used</u> for future planning and program development?

32. What are the most **challenging aspects** of program implementation and why?

# **Outcomes of the Planning Process**

- 33. Do you think the outcomes of the whole comprehensive planning process will lead to expansion and reinforcement of cancer control planning and programming in your state?
  - 33.1. If so, how?
  - 33.2. If not, why?
- 34. How has the planning process affected **interactions among**:
  - 34.1. health department staff,
  - 34.2. health department agencies,
  - 34.3. health department and external organizations, or
  - 34.4. external organizations?
- 35. How did the nature and status of cancer **funding streams** affect efforts to work with organizations or stakeholders in other agencies or outside of the health department?
  - 35.1. Have there been any changes in funding streams, or the way funds are used, that can be attributed to the comprehensive planning process? If so, what happened?
- 36. How did the nature and status of <u>organizational structures</u> affect efforts to work with organizations or stakeholders in other agencies or outside of the health department?
  - 36.1. Have there been any changes in organizational structures that can be attributed to the comprehensive planning process? If so, what happened?

- 37. How did the nature and status of <u>other contextual factors</u> affect efforts to work with organizations or stakeholders in other agencies or outside of the health department?
  - 37.1. Have there been any changes in contextual factors that can be attributed to the comprehensive planning process? If so, what happened?
- 38. How did the planning process affect the way that **cancer-related data** are compiled and used?
- 39. Have **program priorities changed or been adjusted** to reflect shifts in needs of the population based on planning?
- 40. Has (Will) the planning process (be) continued beyond the previous (current) planning cycle? How will the lessons learned from the prior planning cycle feedback to the current (or future) one?
- 41. How do you think the cancer control planning and program implementation process has improved (is being improved) as a result of comprehensive planning?

### Conclusion

- 42. Based on your experience, what advice would you give to other States that are beginning a planning process?
  - 42.1. What do you wish you had known when you started?
  - 42.2. What kind of help would have been useful to you?

Ask if the Notetaker has anything questions or clarifications.

# Interview Guide A–C State Program Director, Planning Managers, & Program Managers

# **Comprehensive States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

#### **Orientation**

- 43. I would like to learn more about **your position** here. What is your job title and what are your responsibilities?
  - 43.1. Program decision—making authority? (i.e., what will or will not be done)
  - 43.2. Funding authority?
- 44. We understand that you (had/are planning) [insert very brief statement of actual or proposed cancer prevention and control planning] in this State. Can you briefly **describe your involvement** in that process?
  - 44.1. When did you become involved in the planning effort?
  - 44.2. How and Why did you become involved?
- 45. How did the **health department become involved** in the comprehensive planning effort?

46.	Is this	the first time your state has undertaken a state—wide cancer planning effort?
	46.1.	If not, how many times and when?
47.		s) there <u>a <b>planning body</b></u> , such as a coalition or committee, and did you have cant interaction with it?
<u>Ob</u>	<u>jective</u>	<u>Setting</u>
48.		are the <u>cancer prevention and control objectives</u> defined in the planning is (if they already have been defined?)
	48.1.	Can the state health department produce written objectives?
	48.2.	Is the authority to produce written objectives a result of undertaking comprehensive planning or has the health department always been able to do so?
49.		were/are) cancer control objectives developed and defined in your states ag process?
	49.1.	Timing?
	49.2.	People involved and how?
	49.3.	Role of HD?
	49.4.	Reps of minority and advocacy groups?
	49.5.	Consensus/agreement among planners? If so, how? If not, why?
	49.6.	Needs assessment?
	49.7.	Data-epidemiological, financial and health care utilization?
	49.8.	Other results?

50. What are the most **challenging aspects** of defining objectives and why?

### **Program Components (Interventions)**

- 51. <u>How</u> were program components (interventions) scientifically likely to lead to achievement of program objectives <u>identified</u>?
  - 51.1. Role of the HD?
  - 51.2. Timing?
  - 51.3. People involved and why?
  - 51.4. Rep. of minorities/advocacy?
  - 51.5. Was/is there an effort to <u>compare alternative intervention strategies</u> to identify those most appropriate for the state?
  - 51.6. How were/are potential interventions <u>reviewed for scientific evidence</u> of effectiveness, efficacy and cost effectiveness?
  - 51.7. How were/are potential interventions **evaluated relative to the needs assessment**?
  - 51.8. What kinds were selected for review, and which ones were ultimately proposed?
  - 51.9. **How were/are they linked** to the comprehensive planning objectives?
- 52. What are the most **challenging aspects** of identifying potential program components and why?

### **Priority-Setting**

- 53. Given the cancer control objectives and the range of possible programs/interventions that could be implemented, **how were (are) realistic programmatic priorities determined**? In other words, how was (will) it (be) decided what could be done to achieve the objectives in light of the resources available to the health department and its partners?
  - 53.1. Timing?
  - 53.2. People involved and why?

- 53.3. What factors were taken into consideration when determining programmatic priorities? Why these factors?
- 53.4. What were <u>the results of the priority-setting process</u> and <u>why</u> were the selected programmatic priorities settled upon?
- 54. What are the most **challenging aspects** of setting program priorities and why?

### **Implementation**

- 55. What **kinds of programs (have been/will be) implemented** or revised as a result of the planning process?
  - 55.1. Timing
  - 55.2. What kinds of cancer prevention and control activities (are currently operating/could be started) that might not (happen/have happened) if this planning process (had never occurred/never occurs)?
  - 55.3. What <u>kinds of site-specific or risk-factor specific programs</u> have been implemented as part of a comprehensive planning process (e.g. cross-referral, exchange of informational materials, etc.)?
- 56. Who is responsible for the implementation of the intervention programs
  - 56.1. If implementation is carried out by other than SHA, what is the relationship if any at all?
  - 56.2. What <u>resources (did/can) the health department provide</u> to the program implementations from its own staff and funding?
  - 56.3. What <u>resources</u> (were brought/will be sought) in <u>by other agencies of state</u> and local government and/or the private sector in support of the implemented programs?
  - 56.4. Have <u>linkages</u> established during the previous planning phases been <u>used to</u> support implementations? (Or will they be?)

- 57. What <u>outcomes</u> have resulted from program interventions <u>linked to</u> the comprehensive planning process?
  - 57.1. <u>Have any evaluations been done</u> and what have these shown about efficacy, effectiveness and cost effectiveness? (Or will they be?)
  - 57.2. Have (Will) **the results of program evaluations been (be) used** for future planning and program development?
- 58. What are the most **challenging aspects** of program implementation and why?

# **Outcomes of the Planning Process**

- 59. Have the outcomes of the whole process led to expansion and reinforcement of comprehensive cancer control planning in your state?
  - 59.1. If so, how?
  - 59.2. If not, why?
- 60. How did the planning process affect interactions among:
  - 60.1. health department staff,
  - 60.2. health department agencies,
  - 60.3. health department and external organizations, or
  - 60.4. external organizations?
- 61. How did the nature and status of cancer funding streams affect efforts to work with organizations or stakeholders in other agencies or outside of the health department?
- 62. Have there been any changes in funding streams, or the way funds are used, that can be attributed to the comprehensive planning process? If so, what happened?

63.	How	did t	he j	planning	process	affect	the	way	that	cancer	related–	data	are	comp	iled
	and u	used?	)												

- 64. Have program priorities changed or been adjusted to reflect shifts in needs of the population based on planning?
- 65. Has (Will) the planning process continued beyond the previous (current) planning cycle? How will the lessons learned from the prior planning cycle feedback to the current (or future) one?
- 66. Do you think the cancer control planning and program implementation process has improved (is being improved) as a result of comprehensive planning?

# Conclusion

- 67. Based on your experience, what advice would you give to other States that are beginning a planning process?
  - 67.1. What do you wish you had known when you started?
  - 67.2. What kind of help would have been useful to you?

Ask if the Notetaker has anything questions or clarifications.

# Interview Guide C–C Data Management & Surveillance Staff

# **Comprehensive States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

- 1. Can we start by talking about your position here? What is your job title and what are your responsibilities?
  - 1.1. Affiliated with Cancer or Tumor Registry?
  - 1.2. Type of data the person controls.
  - 1.3. The reports for which they are responsible.
  - 1.4. Other data managing organizations or agencies with which they cooperate.
- 2. What kind of data are available to support cancer planning in this state?
  - 2.1. Mortality?
  - 2.2. Morbidity?
  - 2.3. Prevalence?
  - 2.4. Incidence?
  - 2.5. Demographic distribution of disease or risk factors? For what kinds of cancer?
  - 2.6. Health care utilization?

- 3. We understand that there was (is) a state cancer control plan produced (being produced) for this State. Are you familiar with this effort?
  - 3.1. Were (are) you involved in that planning effort, and if so, can you briefly describe your involvement in that process?
- 4. Were (Have) you or your office (been) asked to provide data, research, or analytical support for that planning effort or was there an inquiry about what kinds of data were available?

If yes:

- 5. What kinds of data/analytical support were (have been) requested and by whom?
  - 5.1. Were (Are) requested data available?
  - 5.2. Were (Are) the data actually utilized
  - 5.3. What data were (are) available that the health department failed (fails) to use?
- 6. How were (are) data (being) used to support cancer prevention and control planning and programs?
  - 6.1. Setting objectives?
  - 6.2. Identifying program components?
  - 6.3. Prioritizing?
  - 6.4. Program evaluation?
  - 6.5. Who is using the data?
- 7. Do cancer program staff continue to request data, research, or other analytical support from you or your office?

If yes:

7.1. What data, research, or analytical support are requested?

- 7.2. Who requests the support and for what purpose?
- 8. Do you think the data were (are) well used for cancer prevention and control planning?
  - 8.1. If yes, what was (is) being done right?
  - 8.2. If not, why?
- 9. What are the most difficult or challenging aspects related to the generation and use of data for cancer prevention and control?

- 9.1. Epidemiological and surveillance?
- 9.2. Demographics
- 9.3. Health care access and utilization
- 9.4. Other
- 10. How could data be better used for cancer control planning?

i.e., if it were to be done again, how could data be used more effectively for cancer control planning?

Ask if the Notetaker has anything questions or clarifications.

# Interview Guide D–C Coalition Leaders & Members

# **Comprehensive States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

# **Orientation**

- 1. We are here to talk about your work as part of the [name of advisory body]. How are you involved in it?
  - 1.1. What is the nature and extent of your activities as a member?
  - 1.2. How long have you been involved?
  - 1.3. How did you become involved in the first place?
  - 1.4. Is there a professional or personal reason for being there?
- 2. Can you tell me something about [the advisory body] itself?
  - 2.1. Why was it established?
  - 2.2. When?
  - 2.3. Who is on it and how stable is the membership?
  - 2.4. Minorities and advocates?
  - 2.5. What is the relationship to state HD?
  - 2.6. How often does it meet and what is the purpose of the meetings?

# **Planning Process**

- 3. We understand that the [advisory body] was part of (is participating in) a state planning process for cancer prevention and control that also involved the State Health Department? How was (is) the [advisory body] involved in the planning process?
  - 3.1. Setting objectives?
    - 3.1.1. Timing
    - 3.1.2. People involved?
  - 3.2. Identifying program components?
    - 3.2.1. Timing
    - 3.2.2. People involved?
  - 3.3. Determining priorities?
    - 3.3.1. Timing
    - 3.3.2. People involved?
- 4. How were (have) you personally (been) involved in the planning process?
  - 4.1. What committees were you involved in and how?
- 5. Were any data considered in setting objectives, prioritizing programs., etc. What kind and how were they used?
  - 5.1. Were you involved in obtaining and/or using the data?
  - 5.2. Challenges in using data?

*If process has moved to program implementation, then:* 

6. What programs have been implemented as a result of [the advisory body's] participation in program planning and development?

- 6.1. What resources or expertise was contributed to these programs by members of the [advisory body]? Can you give us an example?
- 6.2. How are you and your organization involved in implementation?
- 6.3. Have any of the programs been evaluated? If so, what were the results?
- 6.4. Challenges in program implementation?

# **Outcomes of Comprehensive Planning**

7.	Have the outcomes of the whole process led to expansion and reinforcement of
	comprehensive cancer control planning in your state?

- 7.1. If so, how?
- 7.2. If not, why?
- 8. How did the planning process affect interactions among advisory body members and the health department?
- 9. Have the relationships established among stakeholders for the purpose of cancer planning been maintained and/or strengthened as a the intiative has moved on to implementation?
  - 9.1. Why or why not?
  - 9.2. Challenges?
- 10. How did the nature and status of cancer funding streams affect efforts to work with organizations or stakeholders in other agencies or outside of the health department?
- 11. Have there been any changes in funding streams, or the way funds are used, that can be attributed to the comprehensive planning process? If so, what happened?

	ow did the planning process affect the way that cancer-related data are compiled ad used?
	ave program priorities changed or been adjusted to reflect shifts in needs of the opulation based on planning?
	o you think the cancer control planning and program implementation process has approved (is being improved) as a result of comprehensive planning?
	ny advice that you would pass on to other coalitions in other States that are just eginning a similar planning process?
Ask t	f the Notetaker has anything questions or clarifications.  he Interviewee if they have anything they would like to say or add before we
end tl	he interview.

# Interview Guide E–C State Legislator or Staff Person

# **Comprehensive States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

# **Orientation**

- 1. Can we start by talking about your position here? What office do you hold and what are your legislative responsibilities?
  - 1.1. Authority to make decisions about funding of cancer control programs or role in providing information to those who do make such decisions.

### **Planning Process**

- 2. We understand that a planning process for cancer prevention and control was conducted/is being conducted) in this State? Are you familiar with this planning process?
  - 2.1. Were (are) you involved in the planning process, and if so how?
    - 2.1.1. Setting goals and objectives?
    - 2.1.2. Reviewed or been presented with data to support comprehensive cancer planning?
  - 2.2. Does he/she support this initiative? (Only if this has not been established already?)

2.3.	Does he	e/she	hold in	n reservations	about the	planning	process?

- 2.4. What are the advantages of a comprehensive approach to cancer control?
- 3. Has (Does) the planning process include all the important or necessary stakeholders?
  - 3.1. If not, who was left out? Who should be included in the future
  - 3.2. If yes, did he/she play a role in mobilizing support and participation?
  - 3.3. Challenges?
- 4. How did (has) the state of public health funding in [this state] affected the cancer control planning initiative?
  - 4.1. Is it possible for the state government to provide financial support? Why or why not?
- 5. Has comprehensive cancer planning had any impact on legislative or funding priorities in public health in the State?
- 6. What factors favor or disfavor comprehensive cancer planning in this state?
  - 6.1. Why and how?
  - 6.2. Social and political factors (other than funding) that affect cancer control planning and how?
- 7. What kinds of support or assistance are necessary for undertaking a comprehensive approach to cancer control?
  - 7.1. From whom should the support or assistance come?
  - 7.2. What role should the state government play?

Ask if the Notetaker has anything questions or clarifications.

# Interview Guide F–C Community Organization Representative

# **Comprehensive States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

# **Orientation**

- 1. We are here to talk about your work as part of the [name of organization]. Can you tell me something about the organization itself?
  - 1.1. When and Why was it established?
  - 1.2. Mission related to cancer?
  - 1.3. How large is it?
  - 1.4. What is its geographic extent?
  - 1.5. What are the range of its activities?
- 2. What is your position in the organization and how long have you been involved?
  - 2.1. What is the nature and extent of your responsibilities in the organization?
  - 2.2. How did you become involved with the organization?

### **Planning Process**

- 3. We understand that a planning process for cancer prevention and control was conducted (is being conducted) in this State? Are you familiar with this planning effort? What do you know about it? Were (Are) you or your organization involved?
  - 3.1. When, how long, and frequency of participation?
- 4. Why was (is) this organization involved in the planning effort?
  - 4.1. Did (Do) you support the goals and objectives of the cancer planning initiative?
  - 4.2. What did (does) your organization have to gain from the participating in the planning process? What stake do you have in cancer control planning?
  - 4.3. How are the objectives of the planning process similar to the objectives of the organization?
- 5. How were (are) you and/or your organization involved in this planning process?
  - 5.1. Setting objectives?
    - 5.1.1. Timing
    - 5.1.2. With whom?
    - 5.1.3. Contributions of staff and resources?
  - 5.2. Identifying program components?
    - 5.2.1. Timing
    - 5.2.2. With whom?
    - 5.2.3. Contributions of staff and resources?
  - 5.3. Determining priorities?
    - 5.3.1. Timing
    - 5.3.2. With whom?
    - 5.3.3. Contributions of staff and resources?
  - 5.4. Challenges?

- 6. How were (have) you personally (been) involved in the planning process?
  - 6.1. What committees were you involved in and how?

# **Program Implementation**

- 7. Is this organization involved in the implementation of programs that are the result of the planning effort? (Or will it be?)
- 8. How is (will ) the organization involved in implementation, what are (will be) its responsibilities?
  - 8.1. What resources or expertise (will be) are contributed to these programs by this organization? Can you give us an example?
  - 8.2. When did (will) implementation start and how long will it last?
  - 8.3. Who does (will) the organization work with on the specific program(s)
  - 8.4. Has the program been evaluated (are there plans for evaluation)? If so, what were the results?
  - 8.5. Challenges in program implementation?
- 9. How do (can) interventions linked to the planning process utilize or complement the activities of this organization?

### **Outcomes of Comprehensive Planning**

- 10. Can you tell us something about how well the planning process went (is going)?
  - 10.1. Did people agree or disagree about the objectives of planning? What were areas of disagreement?
  - 10.2. Was there a needs assessment and a data-based assessment of alternative interventions?

	10.3.	Has planning continue beyond the first cycle of planning? (Do you think it will?)
11	improv	u think the cancer control planning and program implementation process has ved (is being improved) as a result of comprehensive planning? Has cancer I been improved in this state? (Or will it?)
	11.1.	If so, how?
	11.2.	If not, why?
12		lid participating in the planning process affect interactions between your zation, the state health department, and other organizations in the state?  Have the relationships established among stakeholders for the purpose of cancer planning been maintained and/or strengthened as a the initiative has moved on to implementation? Why or why not?
	12.2.	Challenges in partnerships and collaboration?
13		did the nature and status of cancer funding streams affect this organizations to work with the health department and other agencies?
14		there been any changes in funding streams, or the way funds are used, that can
A -		Notetaker has envelving exections or clarifications
As	k if the	Notetaker has anything questions or clarifications.

# Interview Guide G-C Focus Group Guide

# **Comprehensive States**

Inform F.G. participants of confidentiality measures for this study and request they sign informed consent form. Collect forms and leave second copies for study participants.

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# Set-up (15 minutes)

### *Step 1:*

Put up an overhead or write on the board a definition of comprehensive cancer planning using the CDC definition as :

"an integrated and coordinated approach to reduce the incidence, morbidity, and mortality [of cancer] through prevention, early detection, treatment, rehabilitation, and palliation."

# <u>Step 2:</u>

Put up an overhead or write on a board definitions of "integrated" and "coordinated" as used here.

#### *Step 3:*

Put up the following question:

"What are the advantages of the current cancer control planning and implementation process?"
Discussion (20 min.)
<u>Step 4:</u>
Put up next question:
"What are the challenges and barriers affecting planning and program implementation that the health department and its partners must contend with?"
Discussion (20 min.)
<u>Step 5:</u>
Put up next question:
"What kinds of support or assistance are needed to undertake a comprehensive approach to cancer control?"
Discussion (20 min.)
Guide discussion on the following questions with the following probes:
1. Building partnerships and collaborations throughout the planning/implementation process?
2. Barriers/facilitators in defining objectives?
3. Barriers/facilitators in deciding which interventions to implement?
4. Barriers/facilitators in setting priorities?

5. Assessing whether the planning process is effective in achieving its objectives?

# Wrap-up (20 minutes)

Summarize the discussion around the point raised above and seek additional feedback or clarification on points made.

# **APPENDIX E-2**

**Instruments for Preplanning States** 

### Interview Guide A-P

# **State Program Director**

# **Pre-planning States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

### Orientation

- 68. I would like to learn more about your position in the health department. What is your job title and what are your responsibilities?
  - 68.1. Program decision—making authority? (i.e., what will or will not be done)
  - 68.2. Funding authority?
  - 68.3. How are you involved in the development and implementation of cancer control programs?

*If a previous state planning effort, then:* 

- 69. We understand that there was a previous state cancer control plan produced for this State. Were you involved in that planning effort, and if so, can you briefly describe your involvement in that process?
  - 69.1. When did you become involved in the planning effort?
  - 69.2. How and Why did you become involved?

70. How was the health department involved in the previous planning effort?						
71. Is there a cancer control advisory body, such as a coalition or committee, and do you have significant involvement with it?						
Programs and Implementation						
72. What kinds of programs are currently in place that deal with cancer control from a site–specific, risk–factor specific, or surveillance perspective?						
73. Who is responsible for the implementation or conduct of these programs?						
73.1. If implementation is assisted or carried out by other than SHA, what is the relationship if any at all?						
73.2. What resources does the state health department provide to the program implementations from its own staff and funding?						
73.3. What resources are provided by other agencies of state and local government and/or the private sector in support of the implemented programs?						
74. Have any evaluations been done, or will be done, of program activities?						
74.1. If so, what have these shown about efficacy, effectiveness and cost effectiveness?						
74.2. How might the results of program evaluations be used for future planning and program development?						
75. What are the most challenging aspects of program implementation and why?						

# **Setting Objectives and Prioritizing**

80.5. Data used and How?

76. How does the state decide what cancer control programs to conduct? 77. Are programs related to explicit cancer control goals or objectives? 78. Is there (or has there been) a process by which cancer control goals or objectives are determined and set? 78.1. Timing? 78.2. People involved and how? 78.3. Role of HD? 78.4. Reps of minority and advocacy groups? 78.5. Consensus/agreement? How? 78.6. Data used and How? 78.6.1. Needs assessment? 78.6.2. Data–epidemiological, financial and health care utilization? 79. If any, what are the cancer prevention and control objectives? 80. How are program components (interventions) scientifically likely to lead to achievement of program objectives identified? 80.1. Timing? 80.2. Role of the HD? 80.3. People involved and why? 80.4. Rep. of minorities/advocacy?

- 80.5.1. Was/is there an effort to compare alternative intervention strategies to identify those most appropriate for the state?
- 80.5.2. How were/are potential interventions reviewed for scientific evidence of effectiveness, efficacy and cost effectiveness?
- 80.5.3. How were/are potential interventions evaluated relative to the needs assessment?
- 80.6. What kinds were selected for review, and which ones were ultimately proposed?
- 80.7. How were/are they linked to the cancer control objectives?
- 81. How are realistic programmatic priorities determined, i.e., how is it decided what can be done to achieve cancer control objectives in light of the resources available and other various constraints?
  - 81.1. Timing?
  - 81.2. People involved and why?
  - 81.3. Role of HD?
  - 81.4. Reps of minority and advocacy groups?
  - 81.5. Data used and How?
  - 81.6. What factors are taken into consideration when determining programmatic priorities? Why these factors?
  - 81.7. What are the results of the priority–setting process and why were the selected programmatic priorities settled upon?
- 82. What are the most challenging aspects of setting objectives and determining priorities, and why?

### **Prospects for Comprehensive Planning**

83. What are the important lessons learned from planning and conducting current cancer control programs that could be used to facilitate a comprehensive cancer control approach in this state?

- 84. Is the health department (and its partners) able to use surveillance and other data effectively in planning and conducting cancer control activities? Why or why not?
  - 84.1. What changes would need to occur in the generation and use of relevant data in order to undertake a comprehensive planning effort?
- 85. Are the relationships between the state health department and its partners sufficient or adequate to effectively conduct cancer control programs? Why or why not?
- 86. Who might health department staff need to work with in undertaking a comprehensive approach to cancer control that they have not worked with in the past?
- 87. How might conducting a comprehensive planning process affect interactions among:
  - 87.1. health department staff,
  - 87.2. health department agencies,
  - 87.3. health department and external organizations, or
  - 87.4. external organizations?
- 88. How does the nature and status of cancer funding streams affect current efforts to work with organizations or stakeholders in other agencies or organizations outside of the health department?
- 89. How might the nature and status of cancer funding streams affect efforts to undertake comprehensive planning?

Ask if the Notetaker has anything questions or clarifications.

# Interview Guide B–P State Program Managers & Staff

# **Pre-planning States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

#### **Orientation**

- 90. I would like to talk about your position in the health department. What is your job title and what are your responsibilities?
  - 90.1. How are you involved in the development and implementation of cancer control programs?
  - 90.2. Which program(s) are you involved with?

If a previous state planning effort, then:

- 91. We understand that there was a previous state cancer control plan produced for this State. Were you involved in that planning effort, and if so, can you briefly describe your involvement in that process?
  - 91.1. When did you become involved in the planning effort?
  - 91.2. How and Why did you become involved?
- 92. How was the health department involved in the previous planning effort?

Regardless of previous planning:

93. Is there a cancer control advisory body, such as a coalition or committee, and do you have significant involvement with it?

#### **Programs and Implementation**

- 94. Who is responsible for the implementation or conduct of the program?
  - 94.1. If implementation is assisted or carried out by other than SHA, what is the relationship if any at all?
  - 94.2. What resources does the state health department provide to program implementation from its own staff and funding?
  - 94.3. What resources are provided by other agencies of state and local government and/or the private sector in support of program implementation?
- 95. Have any evaluations been done, or will be done, of the program?
  - 95.1. If so, what have these shown about efficacy, effectiveness and cost effectiveness?
  - 95.2. How might the results of program evaluations be used for future planning and program development?
- 96. What are the most challenging aspects of program implementation and why?
- 97. What other kinds of programs are currently in place that deal with cancer control from a site–specific, risk–factor specific, or surveillance perspective?

# **Setting Objectives and Prioritizing**

101.5. Data used and How?

101.5.1.

- 98. Is your program related to explicit state cancer control goals or objectives? 98.1. What goal or objective is it related to? 99. How does the state decide what the cancer control goals and objectives are? 100. Is there (or has there been) a process by which cancer control goals or objectives are determined and set? 100.1. Timing? 100.2. People involved and how? 100.3. Role of HD? 100.4. Reps of minority and advocacy groups? 100.5. Consensus/agreement? How? 100.6. Data used and How? 100.6.1. Needs assessment? 100.6.2. Data-epidemiological, financial and health care utilization? In the case of your program, how were program components (interventions) scientifically likely to lead to achievement of the cancer control objectives identified? 101.1. Timing? 101.2. People involved and why? 101.3. Rep. of minorities/advocacy? 101.4. Role of the HD?
  - identify those most appropriate for the state?

Was/is there an effort to compare alternative intervention strategies to

- 101.5.2. How were/are potential interventions reviewed for scientific evidence of effectiveness, efficacy and cost effectiveness?
- 101.5.3. How were/are potential interventions evaluated relative to the needs assessment?
- 101.6. What kinds were selected for review, and why was the current one(s) selected ultimately?
- 102. How was it decided what could be done to undertake your program given the need to achieve certain objectives, the range of possible interventions, and the resources available as well as other various constraints?
  - 102.1. Timing?
  - 102.2. People involved and why?
  - 102.3. Role of HD?
  - 102.4. Reps of minority and advocacy groups?
  - 102.5. Data used and How?
  - 102.6. What factors are taken into consideration when determining programmatic priorities? Why these factors?
  - 102.7. What are the results of the priority–setting process and why were the selected programmatic priorities settled upon?
- 103. What are the most challenging aspects of setting objectives and determining priorities, and why?

#### **Prospects for Comprehensive Planning**

- 104. What are the important lessons learned from planning and conducting your cancer control program(s) that could be used to facilitate a comprehensive cancer control approach in this state?
- 105. Is the health department (and its partners) able to to use surveillance and other data effectively in planning and conducting cancer control activities? Why or why not?

105.1. What changes would need to occur in the generation and use of relevant data in order to undertake a comprehensive planning effort?
106. Are the relationships between the state health department and its partners sufficient or adequate to effectively conduct cancer control programs? Why or why not?
107. Who might health department staff need to work with in undertaking a comprehensive approach to cancer control that they have not worked with in the past?
<ul><li>108. How might conducting a comprehensive planning process affect interactions among:</li><li>108.1. health department staff,</li><li>108.2. health department agencies,</li><li>108.3. health department and external organizations, or</li><li>108.4. external organizations?</li></ul>
109. How does the nature and status of cancer funding streams affect current efforts to work with organizations or stakeholders in other agencies or organizations outside of the health department?
110. How might the nature and status of cancer funding streams affect efforts to undertake comprehensive planning?
Ask if the Notetaker has anything questions or clarifications.
Ask the Interviewee if they have anything they would like to say or add before we end the interview.

# Interview Guide C-P

# **Data Management & Surveillance Staff**

# **Pre-planning States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

- 11. Can we start by talking about your position here? What is your job title and what are your responsibilities?
  - 11.1. Affiliated with Cancer or Tumor Registry?
  - 11.2. Type of data the person controls.
  - 11.3. The reports for which they are responsible.
  - 11.4. Other data managing organizations or agencies with which they cooperate.
- 12. If a previous state planning effort, then:
- 13. We understand that there was a previous state cancer control plan produced for this State. Are you familiar with this effort?
  - 13.1. Were you involved in that planning effort, and if so, can you briefly describe your involvement in that process?
  - 13.2. Were you asked to provide data for that planning effort or was there an inquiry about what kinds of data were available?
  - 13.3. What kind and when?
  - 13.4. Were requested data available?
  - 13.5. Were the data actually utilized, and if so, how were they used?

14	. What kind	of data are available to support cancer planning in this state?
	14.1.	Mortality?
	14.2.	Morbidity?
	14.3.	Prevalence?
	14.4.	Incidence?
	14.5.	Demographic distribution of disease or risk factors? For what kinds of cancer?
	14.6.	Health care utilization?
15	. Do cancer office?	program staff request data, research, or other analytical support from you or your
16	. If yes:	
	16.1.	What data, research, or analytical support were requested?
	16.2.	Who requested the support and for what purpose?
17	. Do you ha	ve available the data that they request?
	17.1.	What data are unavailable that the health department would like to use?
	17.2.	What data are available that the health department fails to use?
18	. How are d	ata used to support cancer prevention and control planning and programs?
	18.1.	Setting objectives?
	18.2.	Identifying program components?
	18.3.	Prioritizing?
	18.4.	Program evaluation?
	18.5.	Who is using the data?

- 19. Do you think the data are well used for cancer prevention and control planning?
  - 19.1. If yes, what is being done right?
  - 19.2. If not, why?
- 20. How could data be better used for cancer control planning, particularly for a future comprehensive planning effort?
- 21. What are the most difficult or challenging aspects related to the generation and use of data for cancer prevention and control?
  - 21.1. Epidemiological and surveillance?
  - 21.2. Demographics
  - 21.3. Health care access and utilization
  - 21.4. Other

Ask if the Notetaker has anything questions or clarifications.

Ask the Interviewee if they have anything they would like to say or add before we end the interview.

# Interview Guide D–P Coalition Leaders & Members

# **Pre-planing States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

- 16. We are here to talk about your work as part of the [name of advisory body]. How are you involved in it?
  - 16.1. What is the nature and extent of your activities as a member?
  - 16.2. How long have you been involved?
  - 16.3. How did you become involved in the first place?
  - 16.4. Is there a professional or personal reason for being there?
- 17. Can you tell me something about [the advisory body] itself?
  - 17.1. Why was it established?
  - 17.2. When?
  - 17.3. What is the relationship to state HD?
  - 17.4. What are the range of its activities?
  - 17.5. How often does it meet and what is the purpose of the meetings?
  - 17.6. Who is on it and how stable is the membership?
  - 17.7. Minorities and advocates?

*If a previous cancer planning effort, then:* 

- 18. We understand that there was a previous state cancer control plan produced for this State. Were you involved in that planning effort, and if so, can you briefly describe your involvement in that process?
  - 18.1. When did you become involved in the planning effort?
  - 18.2. How and Why did you become involved?
  - 18.3. How was the [the advisory body] involved in the previous planning effort?
  - 18.4. What was the role of the Health Department in this process?

*If participant, or advisory body, was not involved in previous planning efforts, then:* 

- 19. How have you or other members of [the advisory body] participated in the planning and implementation of cancer prevention and control programs in this state?
  - 19.1. Setting objectives?
    - 19.1.1. Timing
    - 19.1.2. People involved?
  - 19.2. Identifying program components?
    - 19.2.1. Timing
    - 19.2.2. People involved?
  - 19.3. Determining priorities?
    - 19.3.1. Timing
    - 19.3.2. People involved?
  - 19.4. Data used and How?
  - 19.5. Challenges?
- 20. What programs have been implemented as a result of [the advisory body's] participation in program planning and development?
  - 20.1. What resources or expertise was contributed to these programs by members of the coalition? Can you give us an example?

20.2.	Have any of them	been evaluated?	If so, what	were the results?
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# **Prospects for Comprehensive Planning**

- 21. What are the important lessons learned from planning and conducting current cancer control programs that could be used to facilitate a comprehensive cancer control approach in this state?
  - 21.1. In general, what are the barriers to comprehensive cancer planning in this state?
- 22. Are there sufficient data, in terms of availability and quality, to be used effectively in planning and developing cancer control programs? Why or why not?
  - 22.1. What changes would need to occur in the generation and use of relevant data in order to undertake a comprehensive planning effort?
- 23. How should [the advisory body] and the state health department work together in undertaking a comprehensive planning effort?
  - 23.1. What organizations or people should be involved in this effort who are not part of the [advisory body]?
  - 23.2. Minority/advocacy organizations?
- 24. How does the nature and status of cancer funding streams affect current partnerships between stakeholders in this state, including [the advisory body] and the state health department?
- 25. How might the nature and status of cancer funding streams affect efforts to undertake comprehensive planning?

<sup>20.3.</sup> Challenges?

Ask if the Notetaker has anything questions or clarifications.

Ask the Interviewee if they have anything they would like to say or add before we end the interview.

# Interview Guide E–P State Legislator or Staff Person

# **Pre-planning States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

#### **Orientation**

- 8. Can we start by talking about your position here? What office do you hold and what are your legislative responsibilities?
  - 8.1. Authority to make decisions about funding of cancer control programs or role in providing information to those who do make such decisions.

## **Planning Process**

If a previous cancer planning effort, then:

We understand that there was a previous state cancer control plan produced for this State. Were you involved in that planning effort, and if so, can you briefly describe your involvement in that process?

When did you become involved in the planning effort?

How and Why did you become involved?

Setting objectives?

Securing funding for the initiative?

Building coalition?

*If participant was not involved in previous planning efforts, then:* 

Have you been involved in supporting the planning and implementation of specific cancer prevention and control programs in this state, and if so How?

What programs?
Setting goals and objectives?
Securing funding?
Building partnerships?

What are the advantages of the current cancer prevention and control efforts in [this state]?

What are the current challenges or barriers to cancer prevention and control efforts in [this state]?

# **Prospects for Comprehensive Planning**

Do you support the idea of a comprehensive cancer prevention and control planning initiative in this state? (Only if this has not been established already?)

Does he/she hold in reservations about the planning process?

What are the advantages of a comprehensive approach to cancer control?

Who should be included in the planning process so that all the important stakeholders are involved?

Role of HD

Coalition?

Minorities and advocates? Challenges?
How has the state of public health funding in [this state] affected cancer prevention and control to date?
Has the state government to provided financial support? Why or why not?
How will the state of public health funding in [this state] affect the comprehensive cancer control initiative?
Is it possible for the state government to provide financial support? Why or why not?
What factors favor or disfavor comprehensive cancer planning in this state?
Why and how?  Social and political factors (other than funding) that affect cancer control planning and how?
What kinds of support or assistance will necessary for undertaking a comprehensive approach to cancer control?
From whom should the support or assistance come? What role should the state government play?
Ask if the Notetaker has anything questions or clarifications.

Ask the Interviewee if they have anything they would like to say or add before we end the interview.

# Interview Guide F–P Community Organization Representative

# **Pre-planning States**

Inform study participant of confidentiality measures for this study and request they sign informed consent form. Collect form and leave second copy for study participant.

If participant agrees to audio tape recording, START TAPE RECORDER NOW.

## **Orientation**

- 1. We are here to talk about your work as part of the [name of organization]. Can you tell me something about the organization itself?
  - 1.1. When and Why was it established?
  - 1.2. Mission related to cancer?
  - 1.3. How large is it?
  - 1.4. What is its geographic extent?
  - 1.5. What are the range of its activities?
- 2. What is your position in the organization and how long have you been involved?
  - 2.1. What is the nature and extent of your responsibilities in the organization?
  - 2.2. How did you become involved with the organization?

## **Planning Process**

3. If a previous cancer planning effort, then:

- 4. We understand that there was a previous state cancer control plan produced for this State. Were you involved in that planning effort, and if so, can you briefly describe your involvement in that process?
  - 4.1. When, how long, and frequency of participation?
  - 4.2. How and Why did you become involved?
  - 4.3. How was the organization involved in the previous planning effort?
  - 4.4. What was your relationship to the state health department or other planning body?
- 5. Why was (is) this organization involved in the planning effort?
  - 5.1. Did (Do) you support the goals and objectives of the cancer planning initiative?
  - 5.2. What did (does) your organization have to gain from the participating in the planning process? What stake do you have in cancer control planning?
  - 5.3. How are the objectives of the planning process similar to the objectives of the organization?
- 6. If no previous planning efforts, or the organization was not involved, then:
- 7. How has this organization participated in the planning of cancer prevention and control programs in this state?
  - 7.1. Setting objectives?
    - 7.1.1. Timing
    - 7.1.2. With whom?
    - 7.1.3. Contributions of staff and resources?
  - 7.2. Identifying program components?
    - 7.2.1. Timing
    - 7.2.2. With whom?
    - 7.2.3. Contributions of staff and resources?
  - 7.3. Determining priorities?
    - 7.3.1. Timing

- 7.3.2. With whom?
- 7.3.3. Contributions of staff and resources?
- 7.4. Data used and How?
- 7.5. Challenges?
- 8. How have you personally been involved in the planning process?

# **Program Implementation**

- 9. Has this organization been involved in the implementation of specific cancer control programs?
- 10. Why has the organization become involved in cancer–related programs? How does this benefit the organization or relate to its mission?
- 11. How is (has) the organization (been) involved in implementation, what are (were) its responsibilities?
  - 11.1. What resources or expertise are contributed to these programs by this organization? Can you give us an example?
  - 11.2. When did implementation start and how long will it last?
  - 11.3. Who does the organization work with on the specific program(s)
  - 11.4. Has the program been evaluated (are there plans for evaluation)? If so, what were the results?
  - 11.5. Challenges in program implementation?

# **Prospects for Comprehensive Planning**

12. What are the important lessons learned from planning and conducting current cancer control programs that could be used to facilitate a comprehensive cancer control approach in this state?
12.1. In general, what are the barriers to comprehensive cancer planning in this state?
13. What organizations should be involved in an comprehensive planning effort?
13.1. Minority/advocacy organizations?
14. How should this organization and others like it work with the state health department in undertaking a comprehensive planning effort?
15. How does the nature and status of cancer funding streams affect current partnerships between organizations like this and the state health department?
16. How might the nature and status of cancer funding streams affect efforts to undertake comprehensive planning?
Ask if the Notetaker has anything questions or clarifications.
Ask the Interviewee if they have anything they would like to say or add before we end the interview.

# Interview Guide G-P Focus Group Guide

# **Comprehensive States**

Inform F.G. participants	s of confidentiality	measures for	this study :	and request th	ey sign
informed consent form.	Collect forms and	leave second o	copies for s	study participa	nts.

#### START TAPE RECORDER NOW.

## Set-up (15 minutes)

#### <u>Step 1:</u>

Put up an overhead or write on the board a definition of comprehensive cancer planning using the CDC definition as:

"an integrated and coordinated approach to reduce the incidence, morbidity, and mortality [of cancer] through prevention, early detection, treatment, rehabilitation, and palliation."

# <u>Step 2:</u>

Put up an overhead or write on a board definitions of "integrated" and "coordinated" as used here.

## Step 3:

Put up the following question:

"What are the advantages of the current cancer control planning and implementation process?"

Discussion (20 min.)		
<u>Step 4:</u>		
Put up next question: "What are the challenges and barriers affecting planning and program implementation that the health department and its partners must contend with?"		
Discussion (20 min.)		
<u>Step 5:</u>		
Put up next question:  "What kinds of support or assistance would be needed to undertake a comprehensive approach to cancer control?"		
Discussion (20 min.)		
Guide discussion on the following questions with the following probes:		
6. Building partnerships and collaborations throughout the planning/implementation process?		
7. Barriers/facilitators in defining objectives?		
8. Barriers/facilitators in deciding which interventions to implement?		
9. Barriers/facilitators in setting priorities?		
10. Assessing whether the planning process is effective in achieving its objectives?		

# Wrap-up (20 minutes)

Summarize the discussion around the point raised above and seek additional feedback or clarification on points made.

# Appendix F-1. Coding for Comprehensive States

# **NUD\*IST Index Tree Nodes**

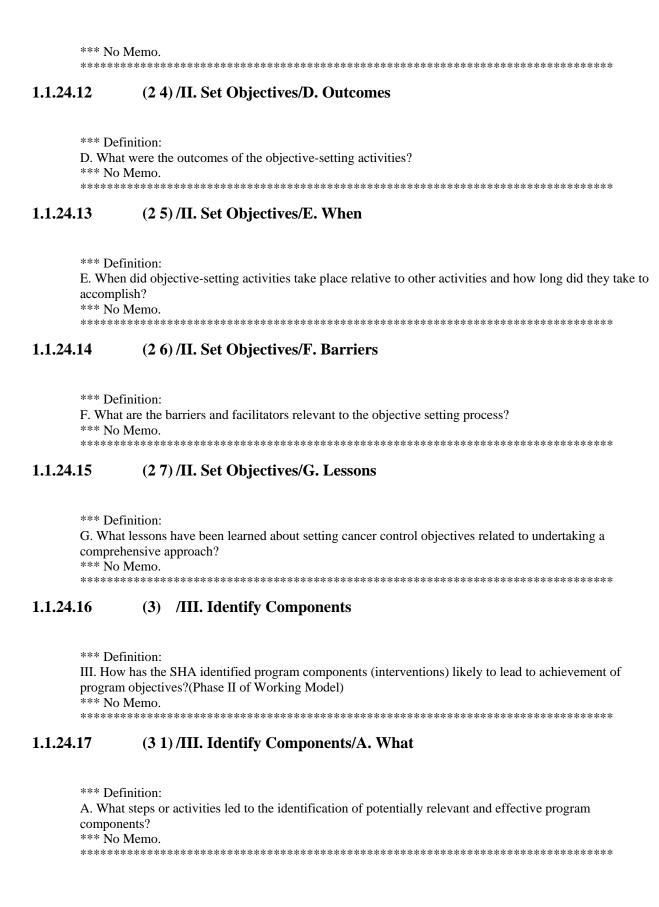
	PROJECT	: NUDIST Comprehensive, User John M Rose, 2:39 pm, May 28, 1998.
	*****	******************
1.1.24.	1 (1)	/I. Structure-Context
	agencies o	re cancer-related programs organized within the state health agency and how do they interact with or programs outside the SHA?
1.1.24.	2 (1 1)	/I. Structure-Context/A. Programs
	comprehe *** No M	programs within SHA that deal with cancer from site-specific risk factor specific surveillance or nsive point of view?
1.1.24.	3 (1 2)	/I. Structure-Context/B. Interact
	attributed *** No M	id heads of programs and staff interact during planning process? Could changes in org. be to comprehensive cancer planning?
1.1.24.	4 (1 3)	/I. Structure-Context/C. New Partners
	attributed *** No M	changes in manner in which data kept and used for specific programs or across programs be to comprehensive planning process?
1.1.24.	5 (1 4)	/I. Structure-Context/D. Funding Impact
	to the con *** No M	changes in interactions between coalition members (planning and program partners) be attributed up. planning process?

# 1.1.24.6 (1 5) /I. Structure-Context/E. Impact of CCPC

\*\*\* Definition: E. Impact of funding streams on efforts to work with people outside of specific programs? Changes in funding, or the way funds are used? \*\*\* Memo: 3:25 pm, May 22, 1998. I.E. What has been the impact of funding streams on efforts to work with people outside of specific programs? Have there been any changes in funding, or the way funds are used, that can be attributed to the comprehensive planning process? \* 1.1.24.7 (2) /II. Set Objectives \*\*\* Definition: II. How has the SHA produced a set of objectives to guide the planning of cancer prevention and control programs? \*\*\* No Memo. \* 1.1.24.8 (2 1) /II. Set Objectives/A. What \*\*\* Definition: A. What steps or activities led to the setting of objectives? \*\*\* No Memo. \* 1.1.24.9 (2 2) /II. Set Objectives/B. Who \*\*\* Definition: B. Who was involved in which objective-setting activities and how were relationships structured? \*\*\* Memo: 3:27 pm, May 22, 1998. RQ II.B. Who was involved in which objective-setting activities and how were relationships structured? (Probe for inclusion of minority, underserved, and survivor/advocacy groups.) \* 1.1.24.10 /II. Set Objectives/B. Who/Minorities-Underserved?  $(2\ 2\ 1)$ \*\*\* Definition: Inclusion of minority, underserved, or advocacy groups in planning/objective setting. \*\*\* No Memo. \* (23)/II. Set Objectives/C. How 1.1.24.11

#### \*\*\* Definition:

C. How were the objective-setting activities conducted?



# \*\*\* Definition: B. Who was involved in which intervention-review activities and how were relationships structured? \*\*\* No Memo. \* 1.1.24.19 (321)/III. Identify Components/B. Who/Minorities-Underserved? \*\*\* Definition: Inclusion of minorities, underserved, or advocacy groups for identifying components \*\*\* No Memo. \* 1.1.24.20 (3 3) /III. Identify Components/C. How \*\*\* Definition: C. How were the intervention-review activities conducted? \*\*\* No Memo. \* 1.1.24.21 (3 4) /III. Identify Components/D. Outcomes \*\*\* Definition: D. What were the outcomes of the intervention-review activities? \*\*\* No Memo. \* 1.1.24.22 (35)/III. Identify Components/E. When \*\*\* Definition: E. When did intervention identification & review activities take place relative to other planning activities & how long did this take to accomplish? \*\*\* No Memo. \* 1.1.24.23 (3 6) /III. Identify Components/F. Barriers \*\*\* Definition: F. What are barriers & facilitators relevant to identification & review of potential program components? \*

(3 2) /III. Identify Components/B. Who

## 1.1.24.24 (3 7)/III. Identify Components/G. Lessons

1.1.24.18

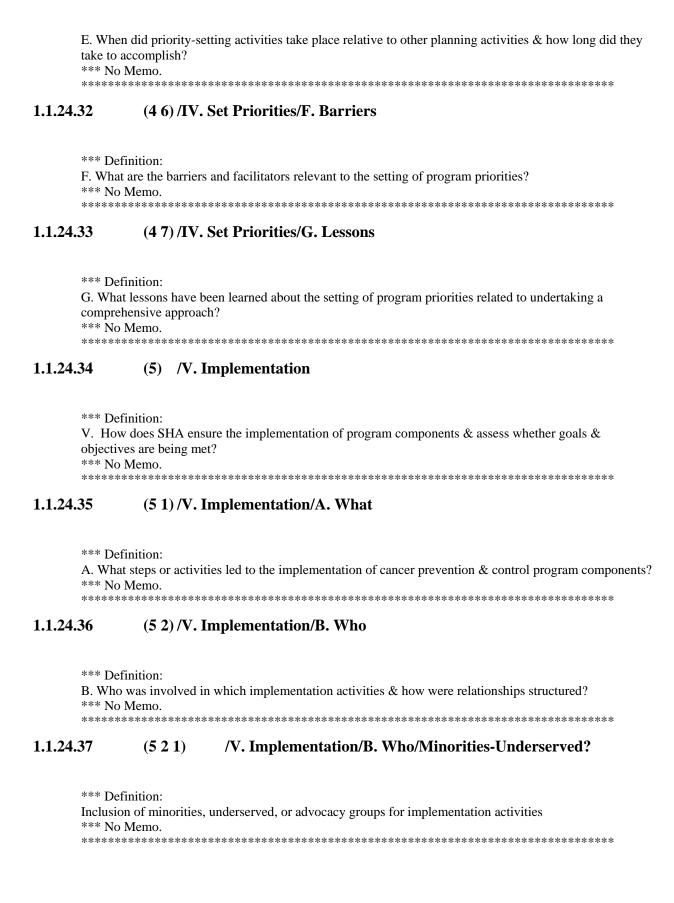
<sup>\*\*\*</sup> Definition:

G. What lessons have been learned about identifying & reviewing potential program components related to undertaking comp. approach?

<sup>\*\*\*</sup> No Memo.

\* 1.1.24.25 (4) /IV. Set Priorities \*\*\* Definition: IV. How does SHA set priorities & determine which program components can be implemented, given available resources & other contextual factors? \*\*\* No Memo. \* 1.1.24.26 (41)/IV. Set Priorities/A. What \*\*\* Definition: A. What steps or activities have led to the setting of priorities among the many tasks that should/could be undertaken? \*\*\* No Memo. \* 1.1.24.27 (42)/IV. Set Priorities/B. Who \*\*\* Definition: B. Who was involved in which priority-setting activities & how were relationships among stakeholders structured? \*\*\* No Memo. \* /IV. Set Priorities/B. Who/Minorities-Underserved? 1.1.24.28  $(4\ 2\ 1)$ \*\*\* Definition: Inclusion of minorities, underserved, or advocacy groups in setting priorities \*\*\* No Memo. \* 1.1.24.29 (43)/IV. Set Priorities/C. How \*\*\* Definition: C. How were the priority-setting activities conducted? \*\*\* No Memo. \* 1.1.24.30 (44)/IV. Set Priorities/D. Outcomes \*\*\* Definition: D. What were the outcomes of the priority-setting activities? \*\*\* No Memo. \*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\* 1.1.24.31 (45)/IV. Set Priorities/E. When

\*\*\* Definition:



# \*\*\* Definition: C. How were the implementation activities conducted? \*\*\* No Memo. \* 1.1.24.39 (5 4) /V. Implementation/D. Outcomes \*\*\* Definition: D. What were the outcomes of the implementation activities? \*\*\* No Memo. \* 1.1.24.40 (5 5) /V. Implementation/E. When \*\*\* Definition: E. When have implementation activities taken place relative to other activities & how long do they take to accomplish? \*\*\* No Memo. \* 1.1.24.41 (5 6) /V. Implementation/F. Barriers \*\*\* Definition: F. What are the barriers & facilitators relevant to program component implementation? \*\*\* No Memo. \* 1.1.24.42 (57)/V. Implementation/G. Lessons \*\*\* Definition: G. What lessons have been learned about program component implementation related to undertaking a comp. approach? \*\*\* No Memo. \* 1.1.24.43 (6) /VI. Feedback \*\*\* Definition: VI. Have the outcomes of the process led to expansion and reinforcement of the cancer planning process? (Whole Working Model) \*\*\* No Memo. \* 1.1.24.44 (6 1) /VI. Feedback/A. Evidence \*\*\* Definition:

(5 3) /V. Implementation/C. How

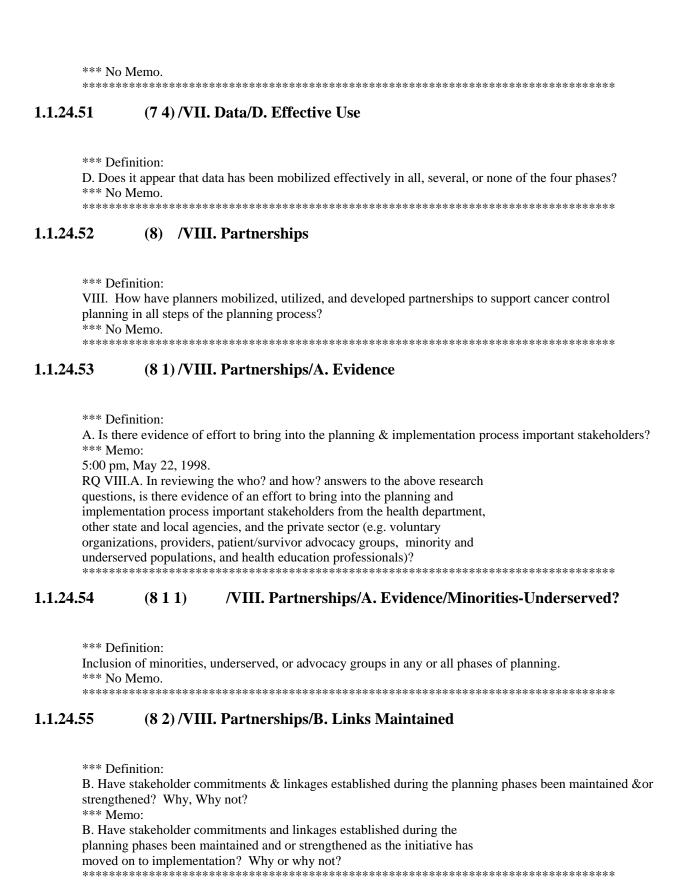
1.1.24.38

learned & how & when did feedback occur? \*\*\* Memo: RQ VI.A. In reviewing the lessons learned? answers to the above research questions, is there evidence of feedback of lessons learned from the prior cancer control activities into the current ones? If so, what were the lessons learned and how and when did the feedback occur? \* 1.1.24.45 (62)/VI. Feedback/B. Improved \*\*\* Definition: B. Do staff think the planning & program implementation process has improved over time? \*\*\* No Memo. \* 1.1.24.46 (6 3) /VI. Feedback/C. How Many \*\*\* Definition: C. How many times has the SHA been through a cancer planning process? \*\*\* No Memo. \* 1.1.24.47 (7) **/VII. Data** \*\*\* Definition: VII. How have planners mobilized, utilized & developed data to support planning in all steps of the process? (Whole Working Model) \*\*\* No Memo. \* (7 1)/VII. Data/A. Types of Data 1.1.24.48 \*\*\* Definition: A. What types of data have been used in the whole planning process? \*\*\* No Memo. \* 1.1.24.49 (7 2) /VII. Data/B. How Use Data \*\*\* Definition: B. How did the SHA and its partners identify, analyze and apply data to setting objectives, identifying program components, and setting priorities? \*\*\* No Memo. \* 1.1.24.50 (73)/VII. Data/C. Barriers

A. Evidence of feedback of lessons learned from prior cancer control activities? What were the lessons

#### \*\*\* Definition:

C. What are the barriers/facilitators and lessons learned from all phases relating specifically to data mobilization, utilization, and development?



# 1.1.24.56 (8 3) /VIII. Partnerships/C. Barriers

\*\*\* Definition: C. What are barriers/facilitators & lessons learned from all phases relating to partnership mobilization, utilization & development? \*\*\* No Memo. \* 1.1.24.57 (9) /IX. Barriers \*\*\* Definition: IX. What are the barriers to comprehensive cancer control planning and implementation, and how should these be addressed? \*\*\* No Memo. \* 1.1.24.58 (91)/IX. Barriers/A. What Within \*\*\* Definition: A. What barriers within state health agency affect planning & program implementation? \*\*\* No Memo. \* 1.1.24.59 (92)/IX. Barriers/B. What Outside \*\*\* Definition: B. What barriers outside health agency affect planning & program implementation? \*\*\* No Memo. \* 1.1.24.60 (93)/IX. Barriers/C. How \*\*\* Definition: C. How are the barriers addressed or overcome? \*\*\* No Memo. \* 1.1.24.61 (94)/IX. Barriers/D. Support \*\*\* Definition: D. What kinds of support or assistance needed to undertake comprehensive approach to cancer control? \*\*\* No Memo. \* 1.1.24.62 (10) /Data Sources

\*\*\* Definition:

Parent node for all data source nodes

\*\*\* No Memo.

\*

## 1.1.24.63 (10 1) /Data Sources/Program Directors

\*\*\* Definition:

All documents for interviews with Program Directors
\*\*\* Memo:

This type includes the individual with supervisory responsibility for cancer prevention and control programming for the state health department. More specifically, health dept. staff whose positions call for the oversight of multiple projects or programs, such as division or office directors who oversee all cancer or cancer related programs, and who supervise the program managers who run the specific programs.

\*

## 1.1.24.64 (10 2) /Data Sources/Program Staff

\*\*\* Definition:

All documents for interviews with Program Staff
\*\*\* Memo:

This type of Study Participant includes: Staff directly involved in managing and/or implementing public health programs for cancer prevention and control. These may be service delivery programs, health promotion programs, or any intervention that might reasonably be expected to be an outcome of a comprehensive cancer planning process.

\*

#### **1.1.24.65** (10 3) /Data Sources/Data Mngmt

\*\*\* Definition:

All documents for interviews with data management, epidemiology, registry or surveillance staff.

\*\*\* Memo:

This includes any person who is directly involved in collecting managing and disseminating public health data on cancer mortality, morbidity, prevalence, incidence or risk factor distribution. This may be someone from the cancer registry or a division responsible for surveillance. This person may come from the state health department or some other state agency. The defining criterion is that this person is involved in producing data on cancer in the state.

\*

#### 1.1.24.66 (10 4) /Data Sources/Coalition

\*\*\* Definition:

All documents for interviews with coalition or advisory body leaders or members.

\*\*\* Memo:

Persons who have been members of a coalition that has conducted or currently conducts state public health planning that incorporates cancer planning. The coalition may be involved solely in cancer planning or cancer planning may be one of several foci of coalition activity. An attempt will be made to identify a past or present coalition leader and

at least one person who is a participant but not a part of coalition leadership. \* 1.1.24.67  $(10\ 5)$ /Data Sources/State Legislator \*\*\* Definition: All documents for interviews with state legislators or their staff persons. \*\*\* Memo: These will be individuals connected to the state legislature and familiar with factors affecting appropriations and funding of public health activities for cancer and other chronic diseases. \* 1.1.24.68  $(10\ 6)$ /Data Sources/Community Org \*\*\* Definition: All documents for interviews with community organization leaders or representatives. \*\*\* Memo: These are members of private voluntary health organizations, grassroots organizations or patient advocacy groups with a stake in the outcome of comprehensive cancer planning. 1.1.24.69 /Data Sources/Other Participant (10.7)\*\*\* Definition: All documents for interviews with study participants who do not fit into the predefined categories. \* 1.1.24.70  $(10\ 8)$ /Data Sources/Focus Group \*\*\* Definition: All documents for focus group interviews \*\*\* No Memo. \* 1.1.24.71 (10.9)/Data Sources/Documents \*\*\* Definition: All documents (internal or external) for documentary evidence. \*\*\* No Memo. \*

# Appendix F-2. Preplanning Case Study Codes

## 1.1.25 (1)Organizational Context

The organizational context for cancer in state government (e.g., position within the HD or super–agency. The macro issues.)

#### 1.1.26 (2) Current Programs

The cancer, cancer-related, and other chronic disease programs in the SHA that currently exist. May also refer to programs undertaken by LHDs, PVOs, or CBOs.

#### 1.1.27 (3)Data Resources

Data resources for cancer planning in the state.

#### (3 1) Types of Data

What types of data are used, or could be used, in cancer control planning?

#### (3 2)How Use Data

How do SHA & partners identify, analyze & use data in support of cancer prevention/control efforts? Or how would they use data?

## 1.1.28 (4) Community Resources

Community resources for cancer planning. Existing or potential planning partners. The important stakeholders for comprehensive cancer prevention and control.

#### (41)Medical centers

Hospitals, cancer centers, clinics, private service provision organizations.

#### (42)Medical Associations

Health care providers and their professional associations.

#### (43)PVOs

Private voluntary organizations, such as the American Cancer Society, American Lung Association, etc.

#### (44)High-Risk & Underserved

All references to minority populations, the medically underserved, or "high–risk" groups as either participants in the planning process or as targets of services.

#### (45)Grassroots-community

Advocacy, survivor, community-based, or grassroots organizations with direct ties to local communities or with special interest populations.

#### (4 6)Others

Any stakeholders or partners that do not fit into the above categories.

#### (47)State Legislators

References to individual state legislators, or groups such as caucuses or committees, who have been involved in some way with cancer control issues.

#### 1.1.29 (5)Interrelationships

The interrelationships between stakeholders and partners that facilitate collaboration or cooperation on cancer prevention and control. Includes formal or informal structures or mechanisms that facilitate interactions.

#### (5 1)cancer-chronic

Cancer programs and other chronic disease programs.

#### (5 2)cancer-other division

Cancer programs and other health dept. divisions.

#### (5 3)HD-other agency

Health dept. programs and other state agencies (not including state legislature)

#### (5 4)HD-external

Health department programs and other external organizations and groups, but not cancer advisory body.

#### (5 5)External-external

Evidence of external Groups working with external groups, but without official involvement of SHA (coalitions etc.)

#### (5 6) HD-Advisory Body

Health department and cancer advisory body

(57)HD–State Legislature

Evidence of the relationship between the SHA and the state legislature (or individual legislators), especially in terms of cancer control.

## 1.1.30 (6)Previous Planning

Previous planning efforts, both cancer and other.

#### (61)Cancer Planning

Previous cancer planning efforts

#### (62)Other Planning

Other previous or current planning efforts, e.g., chronic diseases or the whole SHA.

#### 1.1.31 (7)Barriers

The barriers to cancer control planning and implementation, and how these are or should be addressed?

#### (71)What Within

What are the barriers "within" the state health agency that will affect planning and program implementation?

#### (72)What Outside

What are the barriers "outside" of the state health agency that will affect planning & program implementation?

#### (73)How

How are or could the barriers be addressed or overcome?

#### 1.1.32 (8) Facilitators

Anything that facilitates accomplishing cancer prevention and control planning or implementation.

#### 1.1.33 (9)Support

The kinds of support or assistance needed to undertake a comprehensive approach to cancer control.

#### 1.1.34 (10)Recommendations

Ideas and recommendations about how comprehensive cancer prevention and control should or could work in the state. Major directions Study Participants would like to see the program go, and their thoughts about how they would want to develop plan.

#### **1.1.35** (11) **Discussion**

Case study Team's contextual comments, interpretations, thoughts or ideas *expressed in parentheses or brackets in the interview documents*. These are not "memos," which are recorded for specific documents or nodes if necessary.

#### 1.1.36 (12)SHA Role

The role of the SHA in cancer prevention and control planning and program development, past, present, and future. Includes both discussion of what the role is and what the role should be.

## **1.1.37** (13) Evaluation

Evidence indicating whether evaluations are conducted (past or present) of cancer prevention and control programs, either those of the SHA, local health departments, or other organizations (e.g., ACS).

## 1.1.38 (14)Legislation

Discussion of legislative issues related to cancer prevention and control, including tobacco control. Includes the expression of opinions or ideas (value—laden) about past or present legislation, or "statements of fact" about the content or nature of specific laws.

## 1.1.39 (15)Data Sources

Parent node for all data source nodes. Data source nodes are used to assign documents in the NUD\*IST project to study participant categories or data source types. Allows for easy sorting by data source.

#### (15 1)Program Directors

All documents for interviews with Program Directors

#### (15 2)Program Staff

All documents for interviews with Program Staff

#### (15 3)Data Mngmt

All documents for interviews with data management, epidemiology, registry or surveillance staff.

#### (15 4)Coalition

All documents for interviews with coalition or advisory body leaders or members.

#### (15 5)State Legislator

All documents for interviews with state legislators or their staff persons.

#### (15 6)Community Org

All documents for interviews with community organization leaders or representatives.

#### (157)Other Participant

All documents for interviews with study participants who do not fit into the predefined categories.

#### (15 8)Focus Group

All documents for focus group/group discussion interviews

#### (15 9)Documents

All documents (internal or external) for documentary evidence.