Guidance

for

Comprehensive Cancer Control Planning

Volume 1: Guidelines

Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
4770 Buford Highway, NE
Atlanta, GA 30341

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Throughout this document, we include examples from a group of states that have been crucial in testing and validating the process of comprehensive cancer control. These six model planning states are represented by (states are in alphabetical order): Tina Gill and Lynda Lehing (Arkansas Department of Health); Margie Harris and Jo Hepburn (Illinois Department of Public Health); Julia Francisco, Linda Kenney, and Corinne Miler (Kansas Department of Health and Environment); Jenna Galland, Linda Linville, and Connie Sorrell (University of Kentucky); Barbara Leonard, Peggy Parsons, and Anita Teague-Ruff (Maine Bureau of Health); and Marshall Kano and Katherine Rowley (Utah Department of Health). We also cite information from two states that helped pioneer comprehensive cancer control, Michigan (led by Sue Haviland and Carol Callighan) and North Carolina (led by Marion White).

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Part I

Introduction to

Comprehensive Cancer Control

Section 1—Background

This document presents **guidelines** for developing a comprehensive cancer control (CCC) plan that can be both implemented and evaluated. The information contained in this document is based on the experiences of several states that undertook a comprehensive cancer control planning process in recent years. These states, called "model planning states," included four that had participated in comprehensive cancer control case studies in 1997 and 1998 (Arkansas, Illinois, Maine, and Utah) and two additional states (Kansas and Kentucky). Each of the model planning states worked with a Centers for Disease Prevention and Control (CDC) program consultant and a Battelle Centers for Public Health Research and Evaluation (CPHRE) liaison to go through a planning process to develop a comprehensive cancer control plan. These planning efforts have resulted in the development of the *Guidance for Comprehensive Cancer Control Planning* and the *Toolkit for Comprehensive Cancer Control Planning*. The planning states have agreed to share their insights with other **states, tribes, territories, agencies, and other organizations** (referred to in this document as states and other organizations) interested in planning and implementing comprehensive cancer control.

1.1 How Is This Document Organized?

This document consists of three parts and a Toolkit. Part I serves as an introduction to comprehensive cancer control planning. It consists of this background section (Section 1), and a section that describes creating a vision that will guide the planning process through various stages (Section 2).

Part II is devoted to describing the building blocks of comprehensive cancer control planning. This model is based on the collective experiences of six **model planning states**– Arkansas, Illinois, Kansas, Kentucky, Maine, and Utah. Part II provides considerable detail on each of the building blocks and examples of the **activities** commonly undertaken. It consists of six sections, one for each building block. Each section describes a series of activities for putting

the building block in place. It also contains information taken specifically from the experience of a state that has been engaged in comprehensive cancer control planning for two or more years.

Part III introduces a timeline for comprehensive cancer control planning and previews both implementation of the plan and **institutionalizing** the process.

Most of the guidance document provides specific information to develop a comprehensive cancer control plan and to evaluate it. The toolkit supplements the guidance document and contains materials that planners can adapt or use for their own planning process. Some of these tools were derived from tables, instruments, surveys, questionnaires, or other tools that the model planning states developed as they undertook comprehensive cancer control planning. Battelle CPHRE developed other tools in consultation with CDC's Division of Cancer Prevention and Control to answer a particular need identified by state-based planners. Within the body of the guidance document, readers will see a reference in print—See Tool # – tool title—to let them know where to find tools that may be helpful in supporting the activity being discussed in the text.

Besides the toolkit, the document contains a glossary of terms. Some of these terms are specific to comprehensive cancer control planning. A term that is included in the glossary is set in **bold type** the first time it is introduced in the text of the document. Finally, each section contains a list of references that expands on the materials presented in that section. These references are not exhaustive, but they do represent an expanded body of work available to those who wish to pursue the subjects in more detail.

1.2 What Is Comprehensive Cancer Control?

The CDC defines **comprehensive cancer control** as "an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through **prevention (primary prevention)**, **early detection (secondary prevention)**, **treatment**, **rehabilitation**, and **palliation**."

In what ways is this approach comprehensive? The concept is built on the recognition that effective cancer prevention and control planning and programming should address a continuum of services that range from primary prevention and early detection through effective treatment, quality care, and end-of-life issues, such as pain relief. Comprehensive cancer control

also emphasizes integration of many disciplines including administration, basic and applied research, evaluation, health education, program development, public policy, surveillance, clinical services, and health communications. Comprehensiveness also signifies the inclusion of major cancers, all population groups, and all geographic regions. A comprehensive approach to cancer control is needed because gaps in service delivery and coverage exist. Thus the scope of comprehensive cancer control involves a diverse group of **stakeholders** who must *coordinate their efforts* to implement such a plan. For this reason, the partnership of stakeholders involved in developing the comprehensive plan should also be broad and inclusive. These coordinated efforts usually occur in the context of a formal **collaboration** across multiple disciplines and organizations.

Comprehensive cancer control assesses and then addresses the cancer burden within a given state, tribe, or territory. It builds on the achievements and the infrastructure created for existing cancer programs. Many of these programs address individual cancer sites (breast, prostate) or risk factors (tobacco use, sun exposure). These comprehensive cancer control activities are accomplished through the partnership of stakeholders. The stakeholders carefully review epidemiological data, including data collected by the state central cancer registry and research evidence, and then jointly set priorities for action in a systematic way. The partnership works together to mobilize support to implement the joint priorities that have been established. Finally, the partnership puts in place an evaluation system to monitor implementation progress and to reassess priorities periodically in the light of emerging developments in cancer and other related fields.

Using the experiences of the six model planning states (section 1.5.2), comprehensive cancer control planning can be categorized into the following six areas:

- **Enhance infrastructure.**
- **Mobilize support.**
- **Use data and research.**
- **Build partnerships.**
- **Assess/address the cancer burden.**
- **Conduct evaluation**

These categories represent the building blocks of comprehensive cancer control.

1.3 Why Is Comprehensive Cancer Control Needed?

Although many dedicated people and organizations have made substantial contributions toward reducing cancer incidence, morbidity, and mortality, much remains to be done. The following list of issues, identified by the states, tribes, and territories with whom CDC has worked to develop the comprehensive cancer control process, will no doubt be familiar to others working in the cancer field.

Inadequate infrastructure. Adequate administrative and organizational systems for cancer prevention and control are lacking in most states, tribes, and territories.

Limited resources for cancer control. Resources, including staff and funding, for cancer prevention and control in states, tribes, and territories are limited. Challenges include strong competition for available resources, a lack of flexibility among categorical funding streams, and minimal support for cancer programming from state and local governments.

Limited data use in decision making. Planning decisions are often made on an *ad hoc* basis with little consideration of evidence. Data staff may not be integrated into program planning, and cancer data systems or linkages with other surveillance programs may be inadequate or ineffective. Cancer incidence and treatment data may be underreported. Data analysis may be affected by minimal support, and some data may include misclassification of individuals.

Lack of coordination among cancer control efforts. Focus, integration, and coordination among cancer programs and services and those who provide them may be lacking. Cancer may be a low priority among competing agendas. Practice guidelines may conflict, and health care systems may be fragmented and inequitable.

Heavy and unequal cancer burden. Cancer morbidity and mortality rates are unacceptable and persistently high. Disparities in knowledge, access, treatment, and survival among subpopulations continue.

Insufficient information about effective programs and services. Implemented cancer programs and services are not regularly evaluated. For those that are evaluated, information on what does and does not work is either not disseminated or difficult to assess and use.

To date, observations show that much can be accomplished by undertaking the comprehensive cancer control planning process in a carefully planned manner, as outlined in this

document. The process of initiating and then maintaining a comprehensive cancer control planning effort—even with very limited resources—is what this guidance document addresses.

1.4 How Was the Comprehensive Approach to Cancer Prevention and Control Developed?

The CDC has worked with numerous stakeholders to develop a comprehensive cancer control planning and implementation process. The stakeholders involved in the CDC comprehensive cancer control initiative have been representatives from federal, state, local, and territorial agencies; tribal organizations; organizations serving racial and ethnic minorities; national health organizations; universities and medical centers; private voluntary organizations; professional associations; consumer groups; and other private sector organizations.

Comprehensive cancer control is an extension of CDC's ongoing work with these organizations to enhance the number and quality of cancer-related programs available to the U.S. population. Until recently the cancer-related programs supported by CDC have been primarily categorical in nature and built around specific cancer sites and risk factors. However, CDC staff, **state health agency** staff, and other stakeholders involved in cancer activities increasingly have noted that coordination among these programs is uncommon and have expressed concern regarding duplication of effort and missed opportunities for cancer prevention and control at national, state, and community levels. CDC recognized that further significant growth of cancer prevention and control programs within state health agencies and elsewhere would require coordination and integration of cancer activities to maximize resources and achieve desired cancer prevention and control outcomes.

Enhanced cancer prevention and control programs and services at the national, state, and community levels are ultimately reflected in improved **health outcomes,** yet CDC and its constituents recognize that effective implementation of cancer and other public health programs and services may be hampered by a variety of factors. Often before improvements in health outcomes can occur, improvements in other areas are needed. These may include new organizational structures, increased professional expertise, improved understanding of the challenges of delivering community-based services, health education and health promotion efforts, and increased ability to demonstrate **program outcomes**. Comprehensive cancer control

is a means to develop such critical infrastructure elements by coordinating and integrating cancer prevention and control programs across categorical funding streams and by incorporating the cancer care community. It also provides a means to collaborate across other organizational boundaries, such as those erected by divisions within and among state, tribal, and territorial health agencies; health care systems; and stakeholder organizations and agencies, to name a few.

1.5 What Does Comprehensive Cancer Control Look Like?

In 1994, CDC began formally exploring a comprehensive approach to cancer control. Between 1995 and 1998, CDC conducted a series of meetings and conferences to gather input from stakeholders on the feasibility of implementing comprehensive cancer control at the state level and on potential barriers to and facilitators for the process. Initially, the stakeholders who were involved in developing the concept of comprehensive cancer control had considerable difficulty envisioning a comprehensive approach for their states, tribes, and territories, and they had to find new ways to imagine such a process.

1.5.1 The framework

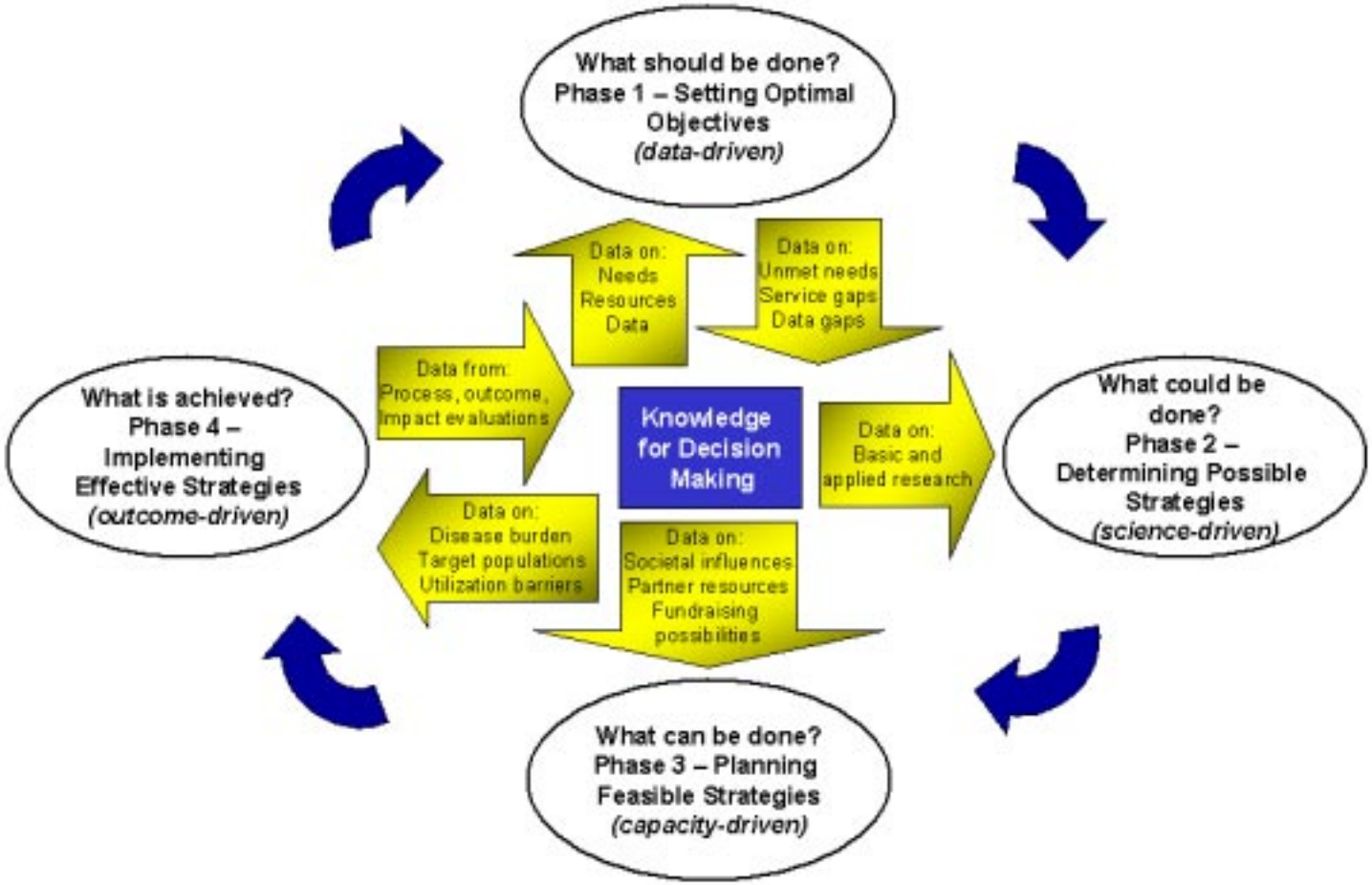
In 1997, CDC began to develop a **framework**, which included a graphical representation, to depict the process through which a comprehensive cancer control plan might be created and then implemented. Ideas and information from various sources, including the experiences of participants in the CDC study, descriptions in the literature of comprehensive cancer planning in the United States and abroad, and existing graphic models for cancer control planning and programming were examined and incorporated into the framework as appropriate. In the framework, data of various kinds are transformed into knowledge for decision making. This decision-making process is undertaken by a group of stakeholders, or partners, and is accomplished by a logical progression of activities that moves from identifying **objectives** through implementing **strategies** to achieve the objectives. Using a systematic priority-setting process, the partner group chooses objectives and strategies that will be implemented. This framework has been published in the *Journal of Public Health Management and Practice* and

can also be found on CDC's comprehensive cancer control Web site (see Section 2—References, page 24).

Figure 1-1 presents the key features of the framework. The framework focuses on four key **phases** of planning: (1) setting objectives based on data, (2) using existing research to determine a range of strategies for meeting objectives, (3) planning strategies that are feasible to implement, and (4) implementing strategies that are effective and yield desired outcomes. The framework emphasizes that comprehensive cancer control is a problem-oriented process that has consecutive phases and is also cyclical in nature. The model clearly moves forward from identifying problems to developing and implementing strategies to resolve those problems. Then, the process begins anew in multiyear cycles of planning, implementation, and evaluation. Although it is difficult to depict in a two-dimensional graphic, the framework may best be seen as an ever-improving process. New data and information enter the system throughout the planning process and lead to an increasingly precise and reliable body of knowledge upon which to base planning and implementation decisions.

The process is an evolutionary one because the review of data and evidence is ongoing. For example, planners may initially obtain epidemiological data that lead them to propose particular objectives for addressing the cancer burden in their state, tribe, territory, or other jurisdiction. Then, research data on effective preventive or treatment **interventions** help support the development of feasible strategies to meet the objectives. Finally, as strategies are implemented, additional data may be required to support effective implementation, such as data on intervention efforts currently under way or data on particular subpopulations that require tailored interventions.

Figure 1.1: Framework for Comprehensive Cancer Control



Source: Adapted from Journal of Public Health Management Practice 2000:6(2):67-78

1.5.2 The building blocks for comprehensive cancer control planning

While a conceptual framework was being developed at the national level, a number of states began the process of comprehensive cancer control planning, and some had begun the **implementation** of existing plans. In 1998, CDC conducted a **case study** in six states to document the cancer control planning process. Two of the states, Michigan and North Carolina, had completed a comprehensive cancer control planning process and offered many lessons and insights. Four states, Arkansas, Illinois, Maine, and Utah, were interested in developing a comprehensive cancer control plan. The case studies in these four states focused on their capacity to develop a plan and their efforts in strategic planning and coalition building. One of the major lessons learned from the case studies was that effective comprehensive cancer control planning generally requires considerable time (up to a year) for **laying the groundwork** before a planning partnership can begin the process.

The states that developed plans and the CDC grantees that implemented comprehensive cancer control plans helped to illustrate what it means to lay the groundwork for planning and to keep this foundation strong. In 1998, CDC provided funding to *five states* and *one tribal health board* that had existing comprehensive cancer control plans: Colorado, Massachusetts, Michigan, North Carolina, Texas, and the Northwest Portland Area Indian Health Board. These organizations were also involved, on an ad-hoc basis, in contributing to the guidelines and affirming the guidance outlined in this document.

The framework was helpful in presenting a theoretical picture of *what* it means to engage in comprehensive cancer control, but it did not provide much information on *how* to develop a comprehensive plan. For this reason, the Building Blocks for Comprehensive Cancer Control Planning model was developed to explain how to develop a comprehensive control plan. The model uses the collective experiences of six **model planning states** (Arkansas, Illinois, Kansas, Kentucky, Maine, and Utah) and provides considerable detail on the **activities** a state or organization might undertake in each of the building blocks.

As seen in Table 1.1, each of the building blocks is directly related to one of the common problem areas identified in Section 1.3

Table 1.1 Relationship Between Identified Problems and the Building Blocks for Planning

Problems Identified by Practitioners of Comprehensive Cancer Control	Building Block	How Problem is Addressed by the Building Block
Inadequate infrastructure for cancer prevention and control in most states, tribes, and territories	Enhance Infrastructure	Develop and enhance the management and administration necessary to support comprehensive cancer prevention and control.
Limited resources for cancer control	Mobilize Support	Improve the use of existing resources for cancer programming and increase the level of support available overall.
Limited data use in decision making	Use Data and Research	Increase extent to which cancer planning and programming decisions are made on the basis of sound evidence, including feedback from routine evaluation of existing and future programs and services.
Lack of coordination among cancer control efforts	Build Partnerships	Increase awareness and involvement of broad sectors of the citizenry in cancer programming and improve coordination and collaboration among stakeholders.
Heavy and unequal cancer burden	Assess and Address Cancer Burden	Reduce morbidity and mortality from cancer overall and reduce disparities in cancer burden among subpopulations.
Insufficient information about effective programs and services	Conduct Evaluation	Develop a strategy for assessing both process and outcomes associated with comprehensive cancer control planning and implementation.

The Building Blocks of Comprehensive Cancer Control Planning Figure 1.2 can be used as a model both for operationalizing the planning process and for evaluating it. The model presents specific activities to be undertaken in a *loosely* defined order. These activities result in a completed, comprehensive plan that can be implemented by a collaborative partnership. The building blocks of the model are either shaded or not shaded. Shaded blocks represent evaluation activities that take place throughout the planning process and throughout each of the building blocks. The first four building blocks in Figure 1.2 (moving from top to bottom) lay the groundwork for planning and provide a strong foundation for the entire process. These building blocks—enhance infrastructure, mobilize support, use data and research, and build partnerships—are set in place early and are strengthened throughout the process. The activities for the sixth building block—conduct evaluation—may begin very early in the process and will certainly continue throughout implementation of the plan. A sound evaluation approach enables planners to determine whether they are staying on target, to provide information to those whose

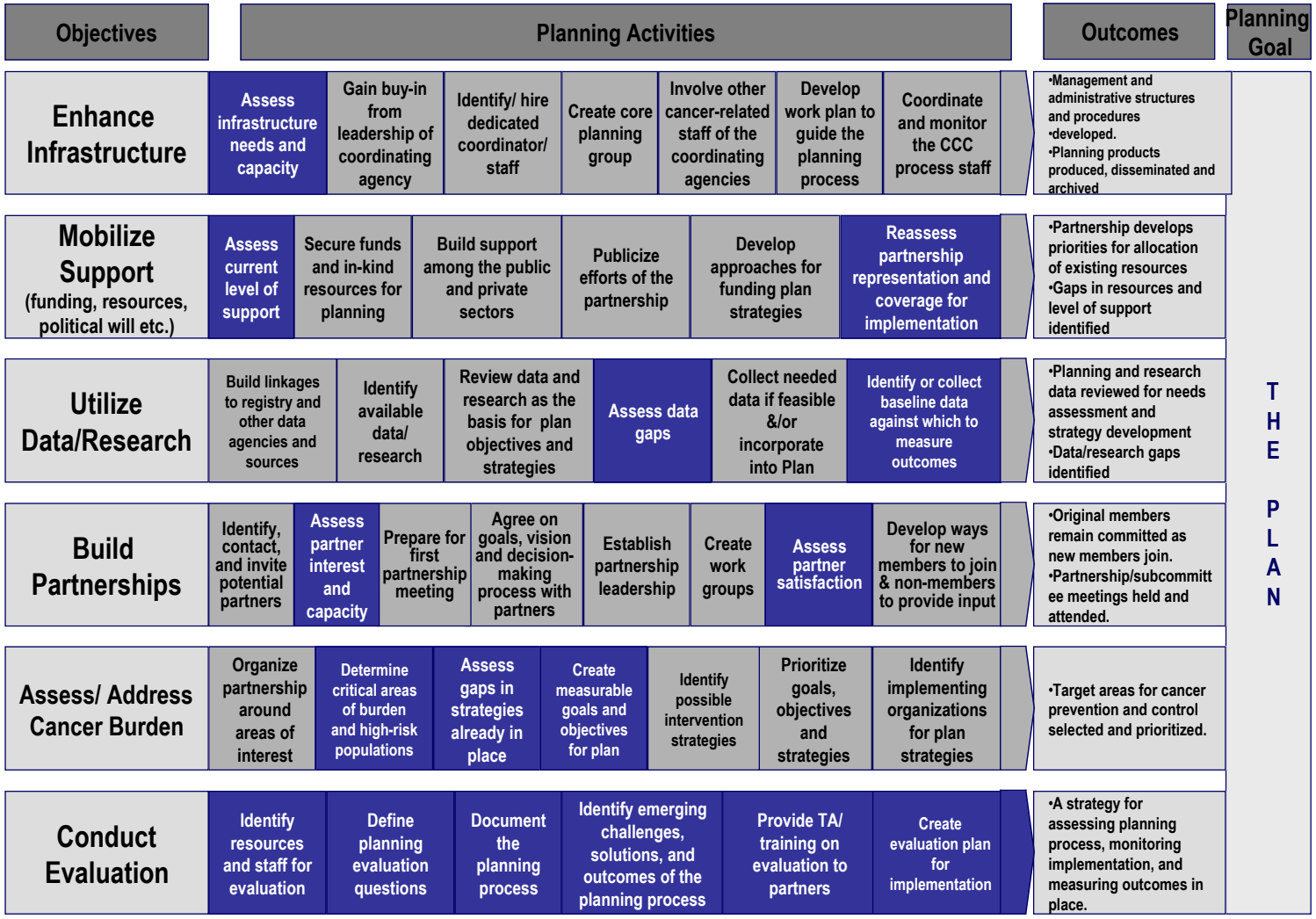
support will enhance the longevity and credibility of the process, and to write planning objectives and strategies that can be measured for success.

The fifth building block in Figure 1.2—assess and address the cancer burden—provides details on the cyclical activities associated with the framework model and describes the crux of what must be done to write a plan that can be implemented and evaluated. However, if conducted prematurely or without support from the other five building blocks, the activities of this building block may well result in a plan that is neither implemented nor evaluated. Table 1.2 shows how each of the building blocks contributes to a more effective process.

Table 1.2 Contributions of the Building Blocks to the Comprehensive Cancer Control (CCC) Process

Building Block	Contributions
Enhance infrastructure	Developing or enhancing infrastructure for planning helps initiate CCC, keeps it on track, and helps the process to progress.
Mobilize support	Support must be mobilized both to permit initiation of the planning process and to sustain implementation and institutionalization.
Use data and research	Data and research must be used to set priorities and to develop strategies to ensure that decisions are based on evidence and are defensible.
Build partnerships	Partnerships must be built to ensure broad buy-in and support for both planning and implementation.
Assess/address cancer burden	This is the cornerstone of the CCC process supported by the other five building blocks. The cancer burden is assessed and then addressed through a broad-based partnership that enhances infrastructure, mobilizes support, uses data and research, and conducts evaluation.
Conduct evaluation	Evaluation must be conducted both to monitor outcomes and to ensure continuous improvement of the process.

Figure 1.2: Building Blocks of Comprehensive Cancer Control (CCC) Planning



1.6 Conclusion

The guidance presented in this document is meant to be flexible. There can be no "one size fits all approach" to something as complex as comprehensive cancer control planning. Five years of research and technical assistance to states and organizations involved in comprehensive cancer control has shown that certain basic elements, or building blocks, should be considered when developing a strategy for comprehensive cancer control planning.

Although the information contained in this guidance document has been drawn primarily from CDC's work with state health agencies or other state-level programs, much of the information can be applied to tribal organizations or territories, and with some adaptation, to local jurisdictions, community-based agencies, and voluntary organizations. Rather than view each activity as a required ingredient in a recipe, planners can feel free to make modifications as appropriate for the environment in which the planning process will be conducted.

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Section 2—Creating a Vision and Strategies for Comprehensive Cancer Control

In a comprehensive cancer control initiative, planning and evaluation go hand in hand. Careful planning for comprehensive cancer control ensures that the initiative is effectively launched and provides a framework for evaluating it. Evaluation activities, in turn, inform planning, help keep the initiative on track, and help analyze its success.

This section is about planning and evaluation and how they interrelate. The concept of creating a vision is used to explore the relationship between planning and evaluation in the comprehensive cancer control context. In this section, creating a vision for the initiative, or comprehensive cancer control planning process, is discussed, as well as using that vision to develop goals, objectives, and strategies for the plan that can be evaluated.

Even before undertaking the goals of the comprehensive cancer control plan, partners must come to an agreement about a number of important issues, such as whether there is a need for pursuing comprehensive cancer control, why it is being undertaken, where it is headed, and how best to get there.

2.1 Designing a Vision and Strategies for Comprehensive Cancer Control

Achieving consensus among partners through some process is a good way to begin a comprehensive cancer control effort. In the next section, a broad process for creating a vision is introduced that can be used to help guide a comprehensive cancer control initiative. The following section describes how the process of creating a vision can be adapted to guide a specific and detailed process that will lead to production of the comprehensive cancer control plan.

2.1.1 Creating a vision to guide the process as a whole

While mapping out the process to meet participants' expectations about comprehensive cancer control, planning staff and their partners should review together broad questions such as why, where, by what route, and how (see Table 2.1)

Major changes, such as those needed to improve cancer prevention and control in the United States, will not occur overnight, yet gradual changes can be expected over time. Thus, having a clear idea of **milestones** likely to be encountered along the way is a means to track progress over time. Describing milestones (or short-, medium-, and long-term results [or outcomes] to be expected from a comprehensive cancer control initiative) is particularly critical. Envisioning short- and long-term outcomes will help participants be specific about what they would like to see change. Similarly, a timeline provides structure and accountability for the desired changes. Once goals, objectives, activities, and outcomes have been established for the initiative, evaluating the process becomes a matter of measuring what the partnership hoped for and what actually occurred.

A vision statement can initially be drafted by the planning coordinator and the **core planning team.** The results are then shared with partners for feedback. A similar process can be undertaken with partners to create a vision statement. Some of the model planning states hired trained meeting facilitators to assist in the creation of their vision with their partnership. This worked well because the staff of the coordinating agency (although more than one agency may be coordinating the effort, for ease of reference, throughout the document we will use "agency") participated in the exercise rather than directing it. Also, in some instances, it is useful for the planning staff to maintain neutrality to encourage the entire partnership to take ownership of the effort. Politics and culture may inhibit some partners from buying in to the process if neutrality is not maintained.

The list of "Basic Questions about State-Level Comprehensive Cancer Control Initiatives" in Table 2.1 may be useful for guiding the planning staff through the comprehensive cancer control process either on their own or with partners. During the summer of 1999, the current practitioners of comprehensive cancer control tested the usefulness of these questions in both the planning and implementation phases. The answers to these questions were a major source of information for the "Building Blocks for Comprehensive Cancer Control Planning

Model" on which this guidance document is based. The reader can use this same list of questions to develop the initiative **work plan**, discussed in Section 3—Enhance Infrastructure.

Table 2.1
Basic Questions about State-Level Comprehensive Cancer Control Initiatives

Why? *What are the central issues your state-level CCC initiative seeks to address?* This question seeks to know partners' opinions regarding what has prompted them to undertake their *CCC* initiative and why they feel such an initiative is necessary. The answers will outline a **problem statement** for the initiative.
Where? *What major change(s) does your CCC initiative hope to bring about?* This question seeks to know partners' views about what their *CCC* initiative seeks to accomplish. The answers will establish a **goal(s)** for the initiative.
By what route? *What must the CCC initiative accomplish along the way in order to achieve the major change(s)?* This question seeks to know partners' views about specific change(s) the *CCC* initiative expects to achieve or accomplish as a means of attaining the broad goal(s). The answers will establish **objectives** for the initiative.
How? *Which broad components or activities that are part of the CCC initiative will lead to achieving each of these interim accomplishments?* This question seeks to know partners' views about specific strategies they would need to undertake as part of the *CCC* initiative to achieve the change specified in the objective(s). These then become the **activities** of *CCC*.
Early Milestones. *How will you be able to tell during the first two years of the CCC initiative whether it is working well?* This question seeks to know partners' views about what they expect to see to indicate that the change(s) the initiative hopes to cause are beginning to occur. Early milestones will represent expected **short-term outcomes**.
Intermediate Milestones. *How will you be able to tell during the first three to four years of the CCC initiative whether or not the initiative is succeeding (i.e., whether some of the desired change(s) are already occurring)?* This question seeks to know partners' views about how midterm signs they expect to see(changes the initiative hopes to cause) are occurring. Intermediate milestones will represent expected **intermediate outcomes**.
Later Milestones. *How will you know if the CCC initiative has, after five years, been successful (i.e., whether some of the desired change(s) have occurred)?* This question seeks to know partners' views about how they would know ultimately that the change(s) specified in their objective(s) has (have) occurred and that the intervention has been successful. Later milestones will represent expected **long-term outcomes**.

2.1.2 Creating strategies for comprehensive cancer control

The process just described involves planning for, and preparing to evaluate, the comprehensive cancer control initiative . Once the partnership is established and consensus is reached around overarching goals and objectives, **work groups** can be formed to address individual topic areas related to cancer prevention and control. Work groups serve a critical function in comprehensive cancer control planning. Sections 6 (Build Partnerships), 7

(Assess/Address Cancer Burden), and 9 (Chronological Overview) have additional information about developing and deploying these work groups. Through the individual work groups, a second and more detailed discussion using the vision may be undertaken. The charge of the work groups will be to identify problems, recommend goals and objectives for addressing these problems, and then to suggest strategies for accomplishing the goals and objectives. To make the case for the need for action in their particular area of interest, the individual work groups will need to answer similar questions in each of the topic areas as those they addressed for the initiative—why, where, by what route, and how.

For the partnership to set reasonable priorities from among the many action items recommended by the work groups, sufficient information is necessary, including answers to such additional questions as the following:

Is the action item feasible? If your goal is impossible to reach, chances are you will never get there.

Where are we now and how far do we want to go? Without knowing where you began or how far you want to go, you cannot measure how much progress you have made or determine how much farther you have to go.

When and for how long? If you are vague about details or the process, you will have no sense of the likely duration of the process or whether the effort is being accomplished in an efficient manner.

With whom? Deciding who will participate, and in what capacity, is critical. Be inclusive.

At what cost? Many planning activities can be done with no money or only in-kind support from partners. However, failing to consider cost may leave you unable to implement or continue activities.

Most partnerships divide into work groups to accomplish the detailed work of planning. Partnership work groups can be organized in a variety of ways such as by cancer (breast, prostate), risk factors (tobacco, sun exposure), the continuum of care (prevention through palliation), or by crosscutting issues (data and surveillance, policy and infrastructure). How groups are structured reflects the members' interests and will likely affect the organization of the plan itself. Work group members often begin their deliberations by thinking in terms of cancer "problems," or what is "wrong" with the way things now stand in relation to the various topic

areas. The coordinating agency should support the partnership by providing it the latest available data before discussions begin to ensure decisions are made with current and accurate data. State central cancer registry data (supported by CDC's National Program of Cancer Registries) or data from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program, and other state-specific data are crucial to a successful plan. To the extent possible, data are provided to demonstrate that each problem exists and for whom. If there is nothing the partnership can do about a problem, there is clearly no point in incorporating it into a comprehensive plan.

Using this information, the partnership creates an issue statement to answer specific questions and concerns for that issue (see Toolkit—tool 16). Based on a given issue statement, goals and objectives are developed to describe how the partnership would like to see the situation improved (goal) and what, specifically, needs to happen to achieve the goal (objectives). Often a single goal is supported by several objectives. Ideally, an objective is SMART—Specific, Measurable, Attainable, Realistic, and Time-phased—and phrased in terms of existing baseline data or an evidence-based description of the status quo. However, formulating SMART objectives is not always possible, especially if baseline data are scarce or unavailable. At minimum, though, the outcomes of well-formulated goals and objectives answer the questions 'where?', 'where from?', 'how far?', and 'how long?' This subject is discussed further in Section 7 (Assess/Address Cancer Burden).

Using the knowledge and expertise of work group members, one or more specific strategies are then recommended as a means to attain the goals and objectives. Strategies should be based on the research literature and on the expertise and experience of the workgroup regarding feasible and effective interventions. Over time, the cumulative effect of implemented strategies would be expected to contribute toward improvements in the identified problem area. A well-formulated strategy answers the question 'how?' and provides more concrete detail than does an issue statement to answer the question 'whether feasible?'

As part of their priority-setting process, some of the model planning states also explored other issues such as which partners would undertake which strategies and whether or not resources currently existed to support implementation. Questions such as 'with whom?' and 'at what cost?' (see page 20) will need to be discussed in greater detail during implementation. Broaching the subjects during the planning phase helps to inject realism into prioritization

discussions and to underscore that implementation does not take care of itself but must be engaged in jointly by the partners and other stakeholders.

A plan compiled in this way will be reasonable, defensible, feasible, and measurable and will likely be accorded broad buy-in by partnership members and other cancer stakeholders in the state, tribe, or territory. Evaluating implementation of the plan will be a straightforward matter of measuring what action was proposed by the partnership against what action actually occurred and with what results.

In Part II, the vision becomes concrete through the Building Blocks of Comprehensive Cancer Control Planning. For a sense of the time needed to put the vision into practice, the reader may refer to Section 9 (Chronological Overview), particularly Tables 9.1 and 9.2. (See also Tool #22—Planning Process Monitoring Sheet).

2.2 Using the Results

Working together toward a common, shared vision is one of the features that set a collaborative partnership apart from more loosely structured groups. Creating a vision helps to forge a collaborative entity capable of implementing a broad mission of cancer prevention and control. Yet these discussions are more than team-building activities. They can also contribute materially and substantially to the creation of a comprehensive plan. The results of the process, for example, can be incorporated into the plan in an introductory section that describes why the partnership has come together and what it hopes to accomplish.

The results of the work groups' more specific and detailed discussions should also be documented in the plan. By the time the plan is produced, each work group will have developed its own problem statements, goals, objectives, and strategies, as well as perhaps timelines, cost, and a list of responsible parties, for a wide range of issues facing a given state. These work group results become the individual draft sections of the comprehensive cancer control plan, underscoring the importance of providing clear instructions and concrete examples of expected work group output to promote standardization and consistency among sections.

The plan also documents the priorities established by the partnership among the recommended courses of action developed by the subject area experts in the work groups. These priorities can be handled in various ways. Illinois, for example, chose to put in its plan only the

six broad priorities that emerged from a multistage selection and refinement process. Maine, which undertook a rigorous and closely observed work group process, included virtually all of the work group output because the goals, objectives, and strategies were evidence-based and defensible and had support from one or more partners. Michigan, an implementation state with a strict priority-setting process, took a dual approach. The state's planning consortium limited the final choice of priorities to a total of 10 that were endorsed for immediate attention. The plan also contained the entire output of more than 100 objectives to acknowledge the breadth of the work groups' efforts.

2.3 Conclusion

In this section, the process of creating a vision has been used as a way of structuring the relationship between planning and evaluation in a comprehensive cancer control initiative. In laying the groundwork for a comprehensive cancer control plan, creating a vision leads to development (by planning staff and their partners) of a broad conceptual framework strong enough to guide the comprehensive cancer control process as a whole and to coalesce members of the partnership over time into a collaborative entity. Using that vision to guide the development of the comprehensive cancer control plan helps guide the work by important subgroups of the partnership to develop reasonable, defensible, feasible, and measurable strategies for implementation by the member organizations.

An integral aspect of comprehensive cancer control planning, a vision also establishes a useful framework for evaluation. Over time, and as it evolves, the partnership's vision can be measured against reality to determine whether the group's goals and objectives are being met at both the initiative level and throughout the development of the plan. More practical aspects of evaluation will be discussed later in this document.

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Part II

The Building Blocks of Comprehensive Cancer Control Planning

Part II—The Building Blocks of Comprehensive Cancer Control Planning

The Building Blocks of Comprehensive Cancer Control Planning can be used as a model for both **operationalizing** the planning process and for evaluating it. For operationalizing the process, the model presents specific activities to be undertaken in a loosely defined order, ultimately resulting in a completed comprehensive cancer control plan. In this section, we discuss the building blocks as a way to initiate comprehensive cancer control planning and complete a plan that can be implemented by a partnership committed to comprehensive cancer control. We will also explain how the model of Building Blocks for Comprehensive Cancer Control Planning can be used to support evaluation of comprehensive cancer control.

As noted in Part I, Section 1, each building block of this model (Figure 1.2), relates to an identified problem, an objective to address that problem, and an anticipated planning outcome. Several building blocks are put in place to lay the groundwork for planning. They are then developed to maintain a strong foundation for the entire process. These building blocks are "Enhance Infrastructure," "Mobilize Support," "Utilize Data and Research," "Build Partnerships," and "Conduct Evaluation". The building block "Assess and Address the Cancer Burden" best describes the process of developing the actual components of a plan that can be implemented and evaluated (see Section 1, Figure 1.1 and Section 7). It is a core process; yet, without the other building blocks, the plan would be incomplete.

Without considering all of the building blocks, the plan…

- **May not be written at all—**due to lack of *infrastructure.*
- **May not be comprehensive in scope—**due to gaps in the *partnership.*
- **May not be defensible—**due to inadequate use of *data and research.*
- **May be difficult or even impossible to implement**—due to lack of *support* in terms of resources and political will.
- **May not appear to be worth doing—**due to lack of *evaluation* data on the outcomes of planned strategies.

Part II of this document is organized into six sections, one for each of the building blocks of planning. Examples of what states have accomplished within each of the building blocks are presented within each section. The activities are discussed in the approximate order in which they occur within the planning process. However, sequential variations are evident among states and organizations, and some activities are ongoing. This variability is likely to continue as new states and organizations undertake comprehensive cancer control. Many building blocks are addressed simultaneously and should be each considered as progressing along their own continuum separately, yet intertwining and moving toward one common goal.

Section 3—Enhance Infrastructure

Lack of staff and other resources can be a significant impediment to beginning a comprehensive planning effort. Yet, experience has shown that it is not necessary to have well-funded cancer programs or a large staff to initiate comprehensive cancer control. Rather, a small group of dedicated and creative professionals can begin a limited process that may well deepen and broaden with time and attention. One planner likened the process to a snowball that increases in size and momentum as it rolls down a hill.

The *objective* of "enhance infrastructure" is to

Develop and enhance the management and administration necessary to support comprehensive cancer prevention and control.

Some *planning outcomes* associated with meeting this objective are

Management and administrative procedures are developed.

Planning products are produced, disseminated, and archived.

Over time, as the plan is implemented and the comprehensive cancer control planning process becomes institutionalized (i.e., the normal way of doing business), partners assume increasing responsibility for a new collaborative entity that is greater than the sum of its parts.

3.1 Activities for Enhancing Infrastructure

3.1.1 Assess infrastructure needs and capacity

An assessment of the strengths and weaknesses of the infrastructure for cancer prevention and control is well worth the time and effort. One veteran health planner expressed the importance of conducting a capacity assessment by stating: "You need to learn who the players are and what's going on in your state in the cancer area. … you also need to have a good science base, an accurate information base among your own staff and partners that they can work

from." The assessment may be focused on the coordinating agency, but if at all possible, some time and energy should be put into assessing the context in which the coordinating agency operates. One approach is to use a tool that includes the following topics: (1) organizational context, (2) cancer programs and related programs, (3) data resources, (4) community resources, (5) past planning efforts, (6) staff skills and experience, and (7) challenges and **facilitators** to comprehensive cancer control. (See Tool #1 Self - Assessing Capacity for Comprehensive Cancer Control Planning in a State).

Some tasks commonly associated with carrying out an assessment include developing a list of respondents, scheduling meetings with respondents to ask questions *or* mail a survey based upon the tool, reviewing written documents that may answer some of the questions (e.g., resource directories, budgets, data displays), analyzing the data obtained using the questions in the tool as a way to organize data, and reviewing the information to understand what it means for the particular state or organization undertaking comprehensive cancer control.

The model planning states that were the original participants in a case study of comprehensive cancer control had the advantage of receiving this baseline assessment. If funds are available, it may be worthwhile to contract with a university or local research firm to conduct an assessment. A baseline assessment can also make an excellent project for a graduate student with faculty supervision, as long as planning staff identify their specific needs. If time and funds are limited, the assessment tool may be modified to focus more narrowly on the capacity of the coordinating agency to begin planning, and further information supplemented later.

3.1.2 Gain buy-in from leadership of the coordinating agency

The impetus for comprehensive cancer control may come from a number of sources, such as the state health agency, the state legislature, cancer agencies, voluntary organizations, or a combination of these. Still, beginning and sustaining the process is difficult without buy-in from the leadership of an agency or agencies that can coordinate or lead the effort. Often, a division director within the state health agency, such as the chronic disease director, begins the process with tentative support from upper management, or a small number of cancer control leaders with support from their own agencies can initiate the process. As partners buy into the process, upper management tends to become more enthusiastic.

Some ways to gain buy-in include

Invite experts in comprehensive cancer control from the federal level, universities, voluntary agencies, research organizations, and from other states to address meetings of leaders whose buy-in would be crucial.

Once leadership has signed off on the initiative, keep them apprised through meeting minutes and any other documentation that is developed, even in the early months.

Comprehensive cancer control staff may attend workshops and conferences and bring materials back to management.

Comprehensive cancer control staff and leaders may develop workshops and conferences on cancer control and invite leadership to speak.

Maine's experience highlights the benefits that support of leadership beyond the level of the chronic disease director can bring to a comprehensive cancer control planning process. The Director of the Division of Community and Family Health (one step below the health agency director) played a critical role in laying the groundwork for undertaking a comprehensive cancer control planning process. He brought cancer-related units into one division within the state health agency, established the Bureau Cancer Team, and obtained cancer control funding from such sources as the National Cancer Institute. Later, he enabled high-level staff to include the comprehensive cancer control planning effort as part of their duties and sponsored efforts to obtain a Public Health Prevention Specialist from CDC to coordinate the effort. Upon initiation of the comprehensive cancer control partnership, he participated in both the core team and the partnership's coordinating committee, which included both health department staff and external partners. Such high-level support provided Maine with the staff and resources to move forward with planning and gave them the credibility to involve high-level partners from organizations external to the state health agency.

3.1.3 Identify or hire a dedicated coordinator and other staff

Case studies and experience with model planning states demonstrated that comprehensive cancer control requires attention from staff. However, it was difficult for most states to dedicate the time and funds to support a full-time coordinator with or without additional staff. Much can be accomplished with a combination of staffing plans.

The key is that someone has primary responsibility for the project and that the primary coordinator has both leadership support and some practical support from his/her supervisor.

In Utah, chronic disease and cancer staff at the state health agency waited until a planning coordinator was hired to begin the process of planning. With his arrival came a deliberate strategy to involve partners so that the state health agency could build a shared vision of the direction in which the planning process should proceed in the best interests of the state. The planning coordinator's regular communication with staff and external partners through well-developed schedules and agendas helped partners to know that the effort was moving forward and was worthy of their time and attention. One staff member stated, "People believe this is going somewhere. If [the planning coordinator's] leadership were to slack off, [the rest of the] people would also slack off."

3.1.4 Create a core planning team

A core planning team or group is generally comprised of staff from the coordinating **agency** for whom cancer and other related chronic disease programming represents a large percentage of their job. No matter how fortunate a state or organization may be in its ability to fund dedicated planning staff, the support of a core planning team enhances the effort by increasing the reach and effectiveness of the staff. A core planning group is crucial when staffing is limited to only one coordinator or a part-time coordinator. Team members need to have time for planning activities and to undertake assignments that are needed for comprehensive cancer control purposes. Some of the kinds of input that team members provide include

Brainstorming and strategizing on a variety of issues such as partners to invite, data resources to be used, or group decision-making procedures.

Researching issues so that recommendations can be made to management and partners.

Collecting data and creating background papers for work groups to use in decision-making.

Making personal connections to key leaders and stakeholders.

Providing staff support to partnership work groups (such as scheduling meetings or preparing and distributing minutes or draft documents).

Writing, editing, and reviewing sections of the comprehensive cancer control plan.

Brainstorming about, and then pursuing, funding or other sources of support.

Assisting with any of the many tasks that occur throughout the planning process.

Although it is unlikely that core team members will have the time to pursue all of these tasks, they will likely provide a "home" for comprehensive cancer control within the coordinating **agency** and accomplish tasks that are feasible in light of other commitments. Among the model planning states, some chose to keep many tasks within the core team. Others were able to depend more on an expanded partnership to carry out tasks. Each state partnership must decide how these processes will be done.

The role of the core planning team in Maine—primarily played by members of the state health agency—was one of leadership, coordination, support, and as a partnership member. The core team did much of the preliminary work to launch the effort, but once the partnership and its coordinating committee were formed, the state health agency sought to downplay its leadership role and served instead only as an involved key participant. Although at least one core team member from the state health agency attended most work group meetings, work group members themselves were encouraged to assume responsibilities (such as meeting facilitation and note-taking) that in other states were performed by health department staff. Having two work group co-chairs for most groups helped spread responsibility. The core team remained central to the planning process throughout the effort. The planning coordinator spent approximately 75 percent of her time on the comprehensive cancer control effort, and other core team members spent 5 to 10 percent.

3.1.5 Involve other cancer-related staff of the coordinating agency

An expanded team provides an opportunity for a range of experts within the coordinating agency, or within the coordinating agency and a few critical partners (e.g., state health agency, American Cancer Society, and an academic medical center's comprehensive cancer center) to

become involved in comprehensive cancer control without requiring the level of commitment associated with the core team. It is also a way to obtain buy-in from people throughout the agency or from key partners before bringing in a full set of partners. The involvement of the expanded team may vary greatly from one that is largely that of providing "advice and consent" to one that requires several hours of work each month—maybe even more at critical junctures in planning.

In Illinois, the expanded team, known as the Internal Advisory Group, played a critical role in initiating the comprehensive cancer control planning process. It is comprised of nine state health agency divisions outside chronic disease with expertise and resources needed for comprehensive cancer control planning. Representatives include staff from Health Policy, Epidemiologic Studies, Health Statistics, Minority Health, Women's Health, Rural Health, Oral Health, Government Affairs, Environmental Health, Behavioral Risk Factor Surveillance System (BRFSS), and Communications.

Three subcommittees of the Internal Advisory Group were formed to help establish and prepare for the Partnership before its first meeting: Data Subcommittee, Task and Timetable Subcommittee, and Partnership Composition Subcommittee. As such, the Internal Advisory Group helped to establish the types of data available, potential partners to contact, and a timeline for completing the planning effort. This group also brought knowledge and lessons learned from previous planning efforts. Internal Advisory Group members continued to participate in the comprehensive cancer control effort as members of the partnership and of individual work groups.

3.1.6 Develop a work plan to guide the planning process

A work plan serves to help keep the project on track. Ideally, it includes a mission or vision statement and broad goals that can be developed through the process described in Section 2. The work plan should also include a timetable with benchmarks, objectives, outcomes, and indicators for meeting those objectives (See Tool #2—Timeline for Planning Tasks). The activities in this guidance document may be used along with the associated objectives and planning outcomes developed as a vision is created for the initiative. The work plan can help

guide the evaluation of the planning process, as well as the development of the comprehensive cancer control plan itself (see Tool #22—Planning Process Monitoring Sheet). It is important to have a written document to guide the process before comprehensive cancer control planning begins in earnest. Otherwise, the process may suffer from a lack of clear direction and the efforts will be difficult to evaluate in a meaningful or systematic way. Further, for enhanced buy-in and support, it is important that, as the work plan is developed, the partnership has input into the final product.

- The Core Team at the Kentucky Cancer Program (KCP) developed a timeline with benchmarks for both completion of the comprehensive cancer control plan and a comprehensive cancer control conference planned for September 2000. Benchmarks included data collection for the plan, the completion of the plan draft, review of the plan by independent reviewers, and the final date for completion and roll out of the plan to be launched at the conference in September 2000.
- In Illinois, the core team worked with the planning coordinator to develop a vision for comprehensive cancer control planning. The planning coordinator also monitored the process using a detailed list of planning activities and dates for completion.
- The Maine and Utah planning coordinators developed timelines of tasks for their state partnership and the respective work groups (See Tool #2—Timeline for Planning Tasks). The timelines served two functions: listing tasks to be accomplished each month (a planning tool) and providing a way to assess progress (a monitoring tool).

3.1.7 Coordinate and monitor the comprehensive cancer control process

This activity requires efficient deployment of limited human resources. One effective way to accomplish the tasks of comprehensive cancer control planning is to assign core team members to work groups to provide staff support. They may take minutes, facilitate work groups, and do much of the day-to-day work that needs to be accomplished between meetings with the approval and direction of the larger partnership. They also report back to the coordinating agency on how well the process is going and what may need to happen to handle any problems that occur. It is important that the coordinating agency and core staff include the partnership in the

decision-making process from the beginning. As this is a statewide effort, a sense of ownership and power must be instilled in all of the partners to ensure a successful initiative.

Kansas provided extensive staff support to its partnership work groups. Each work group was assigned a facilitator to provide logistical support and to facilitate group discussions. The facilitators received training on how to perform their role in a consistent manner. Work groups were also assigned a "backgrounder," who was responsible for compiling and presenting data to the cancer site-specific work groups. These staff were selected because of their expertise in working with epidemiologic data. Some were state health agency staff and some were from other agencies, such as the Kansas Cancer Registry and Kansas University Medical Center.

Additional monitoring of the comprehensive cancer control process can be accomplished through systematic and consistent documentation of planning activities. With the assistance of work group facilitators or chairs, the planning coordinator can keep a chronological log or diary of all planning activities, as well as maintain a central file of all meeting minutes and planning products developed as a result of the activities (See Tool #3—Chronology of Planning Activities).

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Section 4—Mobilize Support

Most professionals working in cancer prevention and control would agree that current resources are limited and need to be increased. Yet, support for an initiative as broad as comprehensive cancer control requires a great deal more than funding. Support comes in various forms, such as in-kind support by providing staff or facilitators, as well as such basic resources as meeting space, meals, or refreshments for partnership members. Support can come from various segments of the community: legislators, a state's executive branch, consumers and patient advocates, the medical community, the business community, representatives of populations within the state, and many others. Modest support early in the process can lead to greater support over time through deployment of community members who have become involved with comprehensive cancer control planning.

The *objective* for "mobilize support" is

> Improve the use of existing resources for cancer programming and increase the level of support overall.

The planning *outcomes* that result from meeting this objective are

> Partnership develops priorities for allocation of existing resources.
>
> Gaps in resources and level of support are identified.

Over time, as the plan is being created and then implemented and the comprehensive cancer control process is institutionalized, the intended outcome of this building block is for existing resources to be better allocated and utilized and resources for cancer control to increase until secure funding for comprehensive cancer control is obtained.

4.1 Activities to Mobilize Support

4.1.1 Assess current level of support

The assessment of existing support can be a part of the case study or baseline assessment discussed under "Enhance Infrastructure" above (See Tool # 1—Self-Assessing Capacity for Comprehensive Cancer Control Planning in a State). At minimum, it should include information on funds available for planning, available staff, potential partners, and the political climate.

Illinois began its planning process with very limited funding during a period of intense organizational change, but with guidance and support from the state health agency's chronic disease director. In the early months, team members identified people and organizations that would likely be supportive of the process but assessed low levels of support from the cancer registry and from upper-level health agency management. The chronic disease director reported on comprehensive cancer control frequently to her supervisors, and the planning coordinator worked closely with the registry. A year later, the registry was actively involved in comprehensive cancer control work groups and the expanded team, and health agency management was expressing enthusiasm for the project as a model for other comprehensive efforts, as well as a willingness to support a modest increase in staffing. A legislative partner sought state funds for comprehensive cancer control. Although the funding bill did not pass during that legislative cycle, this effort is considered a first step for future consideration by the legislature.

4.1.2 Secure funds and in-kind resources for planning

Funds and resources may come from a variety of sources. At first, it may be necessary to "cobble together" sufficient resources to initiate get the planning process. In fact, this approach can be an advantage as it can lead to a commitment from those who participate financially. So far, funding for comprehensive cancer control has come generally from state legislatures,

categorical programs, and federal programs to a modest degrees. Seeking support from other agencies, businesses, and resources is also useful as the comprehensive cancer control process unfolds. This support can begin with in-kind resources, such as meeting rooms, technological support, and meals or refreshments.

Utah wanted to help foster partner ownership and leadership for the planning process from the beginning. One strategy to accomplish this goal was to ask partner organizations to host meetings of the partnership and the work groups. Partners have volunteered their conference space and have provided lunch to meeting participants. Some work group chairs have "donated" administrative staff from their own organizations to take and distribute work group minutes. These in-kind resources have helped the partnership to proceed smoothly, to share leadership responsibilities, and to build capacity and a sense of ownership among partners.

4.1.3 Build support among the public and private sectors

In the long term, support from various sectors of the community may prove as important as early dollar amounts committed by government or highly visible nongovernment partners. These members of the community can be critical in providing input into the comprehensive cancer control plan, in developing future funding, and in implementing the plan. Being inclusive is very important. For example, the business community may prove highly supportive of comprehensive cancer control since some of its strategies (e.g., early detection) could help to keep employee medical insurance costs down in the future.

The Arkansas Comprehensive Cancer Control Initiative made linkages to the Hometown Health Improvement (HHI) Project, a statewide community-level health planning process, with an eye toward implementing the comprehensive cancer control plan at the local level. A Community Development subcommittee within the Arkansas Comprehensive Cancer Control Planning Taskforce was created for this purpose. The Planning Specialist for HHI at the state health agency also serves on the internal work group (expanded team) for comprehensive cancer control. The HHI initiative is convening community decision-makers in seven areas of the state who can serve as front-line representatives for community support once the comprehensive cancer control plan is written. Although the HHI project deals with a range of community issues beyond cancer, the comprehensive cancer control plan can serve as a model of how communities can become involved with cancer control at the local level.

4.1.4 Publicize efforts of the partnership

There are many ways to publicize the comprehensive cancer control planning effort to increase its visibility and gain a broader base of support. Among some of the most popular strategies are special conferences sponsored by the partnership and its members, presentations at public health conferences within a state, and inviting potential supporters (e.g., legislators, business people, community leaders) to partnership meetings. Sometimes asking a busy, but key, member of the community to make a presentation to the partnership on a data-related issue, a particular aspect of cancer care or research, or on outreach to members of minority groups can be helpful. Creativity in publicizing partnership efforts can really pay off as seen in Arkansas and Kentucky, where conferences on comprehensive cancer control planning led to a large outpouring of interest from the grass-roots level up to the state legislature.

Kentucky chose to roll out its comprehensive cancer control plan at a statewide cancer conference, Cancer Awareness Reaching Everyone (CARE). The purpose of the conference was to gather interest and buy-in for implementation of plan strategies. Recipients of invitations included other planning states, members of Kentucky's District Cancer Councils, state and local health departments, cancer registry staff, hospital representatives, field staff, oncologists and other health care providers, health educators, survivors, the Cancer Information Service (CIS), and others. The cancer conference format consisted of panels discussing topics such as surveillance, education, best practices, insurance standards, and quality-of-life issues. The panels concluded with a "Challenge to All" panel to discuss how all Kentuckians can offer leadership for Kentucky's comprehensive cancer control plan and the goals to be achieved.

4.1.5. Develop approaches for funding plan strategies

One of the first tasks necessary for ensuring that strategies are implemented is to develop approaches for funding them. As many public health professionals report from a wide variety of disciplines, one advantage of having an advisory group, coalition, or partnership is that this body is able to lobby the state legislature—something state health agency staff may not be allowed to do. If the planning team determines that resources are clearly needed for either developing the cancer prevention and control infrastructure or for implementing key strategies, then advocating for additional funds is certainly appropriate. Grants or cooperative agreements also may be sought under the partnership's auspices. The coordinating agency is in a stronger position to submit grants for funding when it can draw on the combined expertise of partners. At the same time, each partner should examine the resources that its own organization can bring to the table. Alternatively, partners can take the plan to their respective organizations to determine how that organization as a whole can contribute to implementing the strategies.

Looking beyond usual sources of funding is very important. The Internet is a rich resource for information about both government and nongovernment resources. The partnership may need to be expanded to include members with experience in raising funds. A small amount of funding can be leveraged into further funds and resources once some results are seen from the

process. Therefore, starting small and seeking further funds for larger projects over time is appropriate.

Illinois identified several approaches for funding plan strategies. Despite the lack of state mandated funding for the comprehensive cancer control initiative, these approaches included

1. Creating a Funding and Resources Action Group to look into funding opportunities from various sources (See Tool # 4—Action Group Project Report).
2. Stimulating legislative interest by sending the plan to legislators, sending county-specific cancer profiles to legislators for their districts, monitoring legislative action around the tobacco settlement, and meeting with individual legislators upon request.
3. Encouraging partners and work group members to prepare funding proposals to submit to a variety of funding sources for individual plan priorities (See Tool # 5—Project Proposal for Potential Funding).
4. Submitting several partner proposals to the entire partnership and coordinating agency upper management to elicit support for implementation.

4.1.6 Reassess partnership representation and coverage for implementation

As the partnership moves into implementing the cancer plan, new members may be required who are willing to champion one or more strategies. The implementation stage may be an excellent time to draw in partners who have served as advisors or simply expressed interest in the past, but who were skeptical about participating until they felt assured that the initiative would bear fruit. At this time, the planing team may also opt to identify who may be "missing" entirely from the partnership and can add to its strength as it embarks on implementing the cancer plan.

Most partnerships do, at a minimum, seek out new members, but some partnerships decide to go a step further and restructure the group in preparation for implementing the cancer plan. This restructuring may include developing additional work groups (such as for mobilizing support), altering the function of existing work groups, or involving higher level representatives from partner organizations or even new organizations to aid with implementation. Some

partnerships may go further and decide to completely reconstitute the planning body as a new type of entity for implementing and monitoring the cancer plan. Staff can make decisions about partnership representation and coverage for implementation with the consent of partners or by convening a small group of partners.

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Section 5—Using Data and Research

Accurate and complete data and solid research form the underpinnings for comprehensive cancer control. They help planners to understand the extent of the cancer burden and the existing infrastructure to address that burden. Data and research help ensure that politically popular strategies are also sound. And they help planners to assess the social and policy environments to decide whether or not to move forward with scientifically valid approaches to cancer control. As one planning member in Michigan stated: "Cancer is one of the best opportunities to do evidence-based public health, where we don't implement policies unless we have good science behind them."

The *objective* for "using data and research" is

Increase extent to which cancer planning and programming decisions are made on the basis of sound evidence.

The planning *outcomes* associated with meeting this objective are

Both planning data and research data are used as a basis for needs assessment and strategy development.

Data and research gaps are identified.

Over time, as the comprehensive cancer control plan is implemented and comprehensive cancer control is institutionalized, then gaps in data and research should be addressed through a cyclical process of planning.

5.1 Activities to Utilize Data and Research

5.1.1 Build linkages to the cancer registry and other data agencies and sources

One of the first activities for the coordinating agency is to bring into the process, through participation in either a core or an expanded team, the agencies and individuals with access to data and with the analytic skills to help the partnership make effective use of the data. The cancer registry is key, but other important agencies and individuals should be approached initially, such as insurers and Behavioral Risk Factor Surveillance System (BRFSS) staff. Later, data staff can be called upon to make presentations to partners and to others as the comprehensive cancer control process moves forward. However, if data staff are initially hesitant, demonstrating that comprehensive cancer control planning can help them achieve their own goals, such as increased support for their own programs, may be necessary.

Kentucky and Arkansas demonstrated the benefits of peer mentoring at a time when funding constraints in Arkansas posed a threat to continued operation of the state's cancer registry. The Director of the Kentucky Cancer Registry offered a presentation to the members of the Arkansas comprehensive cancer control expanded team (Internal Work Group) and to others from the state health agency on the importance of the registry to any comprehensive cancer control effort. Leaders in Arkansas suggested that the continued development of the registry be a priority for the state and the comprehensive cancer control plan. A year later the registry had increased funds and staffing, was active in comprehensive cancer control planning, and was working with local communities on identifying risks.

5.1.2 Identify available data and research

As expressed in the Texas Cancer Plan 1998, cancer data are "any data that are relevant to the disease, its risk factors, and its effects, such as mortality, incidence, and survival rates; staging of cancers diagnosed; risk factors; insurance coverage; cost and economic consequences of cancer services; geographic availability of cancer resources; and demographics. In other

words, cancer data are any type of information that can be collected and analyzed to identify trends and gaps in cancer prevention and control." To this list may be added any information that can be used to develop and evaluate strategies for addressing these trends and gaps. The initial assessment of data resources and search for research reports and articles may be undertaken by planning staff and core team members. However, in some settings, partners may be willing or even eager to take on this role. Table 5-1 presents examples of useful data sources for comprehensive cancer control planning. Readers may wish to supplement information in this table with other sources as they are identified (See Tool #7—Data Resource Inventory Sheet).

Table 5.1 Examples of Data Sources Available for Comprehensive Cancer Control Planning

Data Source	Sources	Examples of Uses
Cancer Registries	State Central Cancer Registry SEER Registry	Understand cancer burden in the state.
Health Department Resources	Vital Records	Conduct survival analysis.
	BRFSS–State/County level	Examine rates of preventive behaviors.
	Breast and Cervical Cancer Program (BCCP) Data	Examine rates of benign and malignant breast tumors and of cervical dysplasia or cancer within BCCP population.
	Community Health Assessments	Inform local program, priorities, plans, and implementation.
	Mammography Facilities	Assess number and quality of mammography services.
Data Resources provided by non-health department sources	Insurance data (e.g., HCFA claims)	Conduct cost analyses.
	Cancer mortality rates for minority or other priority populations	Examine cancer burden and risk factors in priority populations.
	Youth Risk Behavior Survey (YRBS) SAMSHA Communities that Care survey	Examine youth behaviors regarding tobacco use and other risk factors.
	American Cancer Society (e.g., survey of patient awareness of services) Cancer Centers (e.g., survey of physicians, physician assistants, and nurse practitioners)	Support initiative to increase patient awareness of services.
	Hospice (hospice services) 1994 Hospital Book National Cancer Registrars Association Directory of Medical Specialists (NCI)	Assess relationship of resources to need.
	Inventory of Linear Accelerator Facilities	Assess gaps in screening capacity and treatment facilities.
	American College of Surgeons Approved facilities, American College of Radiology mammography units	Includes staging, trends of care, and outcome data.
	Cancer Information Services (CIS)	Assess information dissemination to the general public; consumer health profiles.
	Hospital discharge data	Health services utilization matched to needs.
	Legislation, State Cancer Legislative Database (NCI) Legislation, Cancer legislative information (CDC)	Legislative provisions for cancer control and prevention; identify supportive legislators.
	Smoking-Attributable Mortality, Morbidity, and Economic Cost (SAMMEC)	Tobacco consumption, tobacco use, tobacco quit rate, cost of smoking.

Data Source	Sources	Examples of Uses
Special Data Collection Efforts	Expanded BRFSS Cancer-specific surveys	Increase survey data collection to include questions on mammograms, Pap smears, colorectal cancer screening, etc.
	Unmet costs of cancer patients (survey of physicians)	Assess financial burden of cancer care.
	Study to estimate prevalence of cancer	Assess prevalence of cancer.
National Data Resources	National Health Interview Survey (cancer-related disability, pregnancy and smoking, cancer epidemiology) National Death Index NCI Physician Data Query (PDQ) Information System National Cancer Data Links (CDC) NPCR-CSS NAACCR-CINA SEER Cancer Statistics	Assess relationship of resources to need. Population-based cancer incidence data.
	The Guide to Community Preventive Services (www.thecommunityguide.org)	Recommendations for interventions that are successful.
	Current Population Survey, Tobacco Supplement	Population-based smoking information at a national level.

5.1.3 Review planning data and research as the basis for plan objectives and strategies.

This activity is crucial to being able to *assess and address the cancer burden* as discussed in Section 7. Some states or organizations may leave this activity to the staff and the core team; in other instances, partnership work group members are charged with reviewing data and research reports. Not everyone is skilled in analyzing data—understanding how it can be used, what its weaknesses are, or what gaps exist in national or local knowledge. In whatever way the data review is structured, experienced data analysts should be involved to interpret the data. The input from data analysts is very important and directly benefits those charged with using the data to develop objectives and strategies.

In Kansas, "backgrounders"—health department staff and partners with expertise in epidemiology – obtained and presented data to the cancer site-specific work groups (breast, cervical, skin, lung, prostate, colorectal). The work groups reviewed the epidemiological data on cancer sites and then developed issue (or problem) statements that characterized the disease burden in Kansas for that site (See Tool #16—Guide to Developing Issue Statements). Using these statements, objectives for each cancer site were developed. After each work group developed a set of site-specific objectives, the preliminary objectives were grouped under relevant crosscutting issues, and an overarching goal was written for each one. Each objective was further reviewed using the SMART technique to ensure that it was specific, measurable, attainable, realistic, and timephased (See Tool #7—Objectives Litmus Test).

5.1.4 Assess data gaps

In an ideal world, planners would assemble all the available data and find it sufficient to move forward with planning. In reality, this rarely happens. There are always gaps in knowledge and information. Therefore, part of the review described above should include an assessment of what data are not available that would support evidence-based planning. Then an approach can be developed to address these gaps, including (1) leveraging resources that are available to planning partners (See Tool #6—Cancer Resource Inventory Form), (2) collecting data during the plan development process (See Tool #8—Local Health Department Needs Survey), (3) using national data sources to help fill in the gap in state- or local-level data, and (4) incorporating data collection goals and objectives into the comprehensive cancer plan. This assessment may start early and continue throughout the planning and implementation process. The need to assess gaps in data is critical when preparing to decide on plan objectives and strategies.

In Maine, the planning coordinator conducted literature reviews for each work group to identify what information was available and what was lacking. Then, work groups sought to fill in identified data gaps in various ways. For example, after the first meetings of the Treatment Work Group, members conducted their own survey of hospitals and oncologists to gather the data they needed to develop their objectives and strategies. The Palliation Work Group used previously collected data from one of its member organizations. In the absence of surveillance data, members of the Rehabilitation Work Group relied on other sources, such as literature reviews on quality of life for breast cancer survivors. Finally, in some cases, state health agency staff encouraged work groups to add data or evidence generation to their goals. Staff also worked to improve the data available from the state health agency. State specific questions about colorectal and skin cancers have been added to the BRFSS to improve data on risk factors and screening behaviors.

5.1.5 Collect new data if feasible and/or incorporate these activities into plan

In some cases it may be feasible to collect data to fill a recognized need. For example, some partnerships have conducted their own surveys. Examples include population-based surveys to supplement information available from BRFSS, surveys of local health departments to assess needs for cancer education (See Tool #8—Local Health Department Needs Survey), and surveys of physicians and hospitals to identify the unmet costs of cancer patients. Although it is ideal to be able to collect and analyze data before writing plan objectives and strategies, this approach is often not feasible. It is far better to have good data, collected in a rigorous manner, than to base decisions on unsound data. That is why planners frequently incorporate some data collection activities into their comprehensive cancer control plans. For examples of data collection activities conducted during planning, refer to completed cancer plans such as those developed by Texas, Colorado, Massachusetts, Michigan, and North Carolina. Links to these and other resources are available on CDC's cancer Website at http://www.cdc.gov/cancer.

In Illinois, data collection activities are being conducted by action groups upon implementation of the Comprehensive Cancer Control Action Plan, completed in September 1999. For instance, the Cancer Care Assessment action group is assessing assets and gaps in cancer care delivery by surveying 200 hospitals and local health departments (approximately 350 individuals). The survey asks what screening services are provided, when, at what cost, and what special arrangements are available (e.g., van). The focus is on availability rather than current use. The data and surveillance group also conducted a project with the cancer registry to see if melanoma reporting could be increased. This project depended heavily on communicating with the partner organizations' own networks outside of the comprehensive cancer control partnership, such as the Dermatology Association.

5.1.6 Identify or collect baseline data against which to measure outcomes

If at all possible, baseline data should be collected before the plan is completed. Baseline data can demonstrate to the planners what the situation was like before the plan or specific strategies were implemented. Baseline data may be collected early on as part of the process of developing objectives and strategies. They will be necessary for making credible statements later about outcomes of strategies and projects. In some cases, baseline data may not be readily available. If resources to collect these data are very limited, then only identifying how baseline data will be collected as part of the implementation of the strategy or project may be possible.

Kentucky used data extensively as a way to select plan objectives and strategies and to track outcomes. The core team incorporated the objectives from the Kentucky Healthy People 2010 plan, which are measurable, as a way to track the outcomes of its comprehensive cancer control plan. For each objective in the Kentucky Action Plan, the comprehensive cancer control plan lists the data sources that will be used to monitor and evaluate whether the objective has been achieved.

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Section 6—Build Partnerships

Lack of coordination among cancer control programs and services is a problem commonly recognized by stakeholders as one of the chief challenges addressed by comprehensive cancer control. Collaboration is key to any type of comprehensive effort. However, the type of collaboration, level of collaboration, and the people involved may vary greatly depending on the context in which planning occurs. Time is needed to think through the issues associated with developing a collaborative partnership and to prepare to bring partners into the process. Thus, an important step is to initiate some activities within the building blocks of "enhance infrastructure", "mobilize support", and "use data" even before convening the first meeting of the larger partnership.

The *objective* associated with "build partnerships" is

Increase awareness and involvement of broad sectors of the citizenry in cancer programming and improve coordination and collaboration among stakeholders.

The *planning outcomes* that occur when these objectives are met are

Original members remain committed as new members join.

Partnership and work group or subcommittee meetings are regularly held and well attended.

Over time, as the comprehensive cancer control plan is implemented and the comprehensive process is institutionalized, what began as a loose network of organizations and individuals can be forged into a full-fledged collaboration that is capable of concerted advocacy and action.

6.1 Activities to Build Partnerships

6.1.1 Identify, contact, and invite potential partners

In this ongoing activity, core and expanded team members may first list potential partners (See Tool #1—Self-Assessing Capacity for Comprehensive Cancer Control Planning in a State). Then, contact can be made informally, followed by a formal invitation (See Tools #9 and 10—Planning Meeting Invitation Letter and Registration Form). As gaps in the membership are identified, the same procedure may be repeated to enhance the representativeness and inclusiveness of the partnership.

An important step in partnership building is to think through a number of issues associated with developing a membership body. These issues include

What is the role of the partners? Will they be actively developing components of the plan? Will they be providing data and information to others? Will they be writing components of the plan? Will some or all of them be reviewing it? How will roles and relationships be communicated among partners? (See Tool #15—Proposed Structure and Process for Creating a Comprehensive Cancer Control Plan)

Can some partnership roles and functions be divided? For example, does it make sense to have a member body developing goals, objectives, and strategies and then invite other partners or experts to make presentations? Will those who write components also review and vote on them?

Who will lead the partnership? The leadership may come from the coordinating agency, a partner organization, or both.

What is the optimum size of the partnership? It is good to have a group small enough so consensus can be reached on most issues during a single meeting but large enough to include a broad range of partners (probably between 25 and 40 members). If a large partnership is desirable, then developing an executive, coordinating, or steering committee may be necessary. A subcommittee structure that allows for broader participation may help keep the main partnership small in size, and include the broadest group of stakeholders. Potential members should be invited to join as early on in the process as possible.

Should partners represent themselves, their organizations, or some combination? Although the majority of states prefer to have a partnership consisting of representatives of organizations (it is organizations that will need to commit to

implementation), some unaffiliated members, such as consumers, cancer survivors, or retired experts, may need to be included (See Tools #11, 12 and 13—Planning Partner Interest and Commitment Forms).

Although other issues are likely to emerge, answers to the specific questions presented above will help staff to make a list of those organizations and individuals they wish to invite initially. Once they begin to invite some partners, these individuals are likely to know of others who should be invited. In fact, ideas for additional partners can be elicited when contacting the first group of potential partners (See Tools #11, 12 and 13—Planning Partner Interest and Commitment Forms and Tool #14—Planning Partner Surveys.)

Utah used multiple inclusive recruitment strategies to identify, contact, and invite potential partners. First, building on a contact list for a previous breast cancer coalition, health department staff brainstormed about potential partners. These potential partners were then sent a survey to determine their interest in participating; they were asked to identify others who should be at the table (See Tool #14—Planning Partner Surveys.) The planning coordinator also paid personal visits to representatives from key organizations to gain their participation. After the first few meetings, the members of the partnership became a potent recruiting force. Some new partners that joined the partnership after the first meeting had been invited previously but did not attend until someone who was currently on the partnership approached them. The work group members also succeeded in broadening participation on their work groups and in building bridges through their personal and professional networks to other related initiatives in the state and to those staff higher up within their own organizations.

The partners and staff continue to institute other forms of participation. For example, they are reviewing their plan to engage participants (such as providers) who find it difficult to provide input through meetings.

6.1.2 Assess partner interest and capacity

Often, coordinating agency staff are concerned that partners do not want to participate at a high level. However, evidence has shown that organizations with a stake in cancer control are often willing to commit considerable time to the effort as long as there is a clear end-point and a

commitment to use the product after it is developed. In fact, the most active partners express a great deal of personal and professional satisfaction with their involvement in the process. Planners have found that a brief assessment tool can provide a handy way to publicize the initiative while gaining crucial information for developing the partnership.

Utah staff modified a survey originally used in Illinois to determine both the interest level of cancer stakeholders and the resource level of their organizations for a comprehensive cancer control initiative (See Tool #14—Planning Partner Surveys.) Utah's survey had 12 mostly "yes" and "no" and multiple choice questions so that the results would be quantifiable. The survey was sent to 123 cancer stakeholders throughout the state and generated a 54 percent response rate. Of those who responded, 84 percent believed there was a need for statewide comprehensive cancer planning, and 75 percent said they would be willing to serve on a work group or committee. The results from the survey were presented at the first partnership meeting and provided credibility to the effort.

6.1.3 Prepare for the first partnership meeting

The first partnership meeting is a major milestone in the life of a comprehensive cancer control planning process. Before invitation materials are distributed (See Tools #9 and 10– Planning Meeting Invitation Letter and Registration Form), there are many questions to be considered and decisions to be made, such as

Timing of the meeting. How much planning should the coordinating agency already have accomplished before a partnership meeting is called? For example, in Kansas the first partnership meeting was held very early, even before naming a coordinator for the project, as a way to generate buy-in and support. Kentucky took the opposite approach, holding its first partnership meeting after the core team had developed a draft plan.

Agenda for the meeting. What needs to be accomplished? Some states or organizations may simply wish to have an orientation session for their first meeting, but others may go on to develop ground rules and work groups. What is accomplished during an initial meeting will vary according to the resources available, time available (e.g., a half-day or whole day), and the philosophy of the coordinating agency and stakeholders with regard to level of partner participation sought.

The meeting forum. Where should the meeting be held? For many planning bodies, cost is an overriding factor in choosing a venue for the partnership meetings. However, if possible, consider other factors. Holding the meeting at a neutral location, such as a hotel or conference center, may be reassuring to new partners when there are turf issues among stakeholders. The need to hold the meeting in a large population center should be balanced with a desire to include geographically disparate representatives. Offering several videoconferencing sites extends inclusiveness in a large state or one with remote rural populations, as does varying locations for subsequent meetings.

Meeting facilitator. Who should lead the meeting? For the first meeting in particular, engaging a neutral facilitator (someone not associated with the coordinating agency or a major stakeholder) has been found to be extremely useful, but this approach may not always be feasible. Other alternatives may include inviting multiple speakers or asking different persons to lead various sections of the meeting. Still, one person should clearly be in charge of keeping the meeting running smoothly.

To ensure that comprehensive cancer control would be inclusive from the start, Maine decided to host the first partnership meeting at two sites, Portland and Bangor, both representing key regional and population centers in the state. Videoconferencing was used to link the two sites. Aside from communicating the fact that areas of the state outside of the capital are important, this strategy enabled stakeholders from across the state to participate without having to travel too far. Maine also used videoconferencing to include a presentation by representatives from Michigan, a comprehensive cancer control implementation grantee. Maine also brought in an outside consultant to facilitate the meeting, thereby maintaining neutrality among state health agency staff and enabling them to focus on their own substantive participation in the meeting.

6.1.4 Agree on the goals, vision, and decision-making process with the partners

Two general models may be used to accomplish this activity. In the first, staff develop the vision statement, goals, and the beginnings of a decision-making process. The staff might consider proposing one or two alternative decision-making scenarios to the partners. In the second, these three components are developed jointly by the partnership. This activity may be revisited several times with the entire partnership. In Section 2 of this document, the authors offer some ideas on how to approach this activity.

Arkansas used several group decision-making processes to gain buy-in from the stakeholders for the comprehensive cancer control initiative. A decision was made early in the process that the expanded team from the state health agency should come up with the initial vision statement and define the goals of the program. The core team also decided that it should develop a preliminary work plan before bringing in external stakeholders. Then, at the first partnership meeting, external partners agreed on the draft vision statement and broad goals. However, a minority of participants suggested that a new planning effort would be redundant because a cancer plan was already in place. The staff of the state health agency had partners review the existing Arkansas cancer plan to determine if and how it could be used to supplement the new planning effort. After the review, partners and staff decided together that the plan was too focused on breast and cervical cancer to serve as a foundation for a comprehensive approach to cancer control in Arkansas. Partners agreed that the comprehensive cancer control planning process should proceed, and the partnership moved ahead with developing work groups to reflect the vision and goals of the statewide comprehensive cancer control plan under development.

6.1.5 Establish partnership leadership

The leadership structure reflects both a philosophy of planning and the needs of the partnership and should be carefully considered and discussed among partners (See Tool #15—Proposed Structure and Process for Creating a Comprehensive Cancer Control Plan). The leadership of the partnership may be formal or informal. States with legislative mandates tend to have more formal leadership structures as outlined in the enabling legislation. Those states that tried to build partnerships without this legislative mandate tended to feel that too many rules and regulations might alienate potential partners.

Most states allowed the leadership structure to reflect the availability of partners to fulfill specific roles. In general, staff from the coordinating agency, external partners, or a combination of the two sources may fill leadership roles (partnership and work group chairs). Assigning two co-chairs is useful, both for sharing administrative burden and broadening participation. This

approach also eased transition periods when a co-chair had to leave his/her position, either temporarily or permanently.

Maine took a middle road between formal and informal leadership structures and encouraged the active involvement of its partners. Planning staff consciously chose to have open membership and no bylaws, yet they chose a fairly formal multilevel leadership structure for its partnership. The partnership had two co-chairs, an oncologist and a public health professional, to represent both a medical and a public health perspective. A coordinating committee composed of the two co-chairs, several American Cancer Society representatives, and the state health agency core team was also established. The coordinating committee served as the "glue," making sure that the process stayed on schedule and attending to logistics and administrative issues between partnership meetings. External partners were identified to serve as work group co-chairs. These work group co-chairs met together regularly during the objective-setting phase to coordinate cross-group issues.

6.1.7 Create work groups

The work groups accomplish most of the real planning work. A work group structure needs to be established and implemented, and membership for each work group should be recruited (See Tools #11, 12, and 13—Planning Partner Interest and Commitment Forms). Different model planning states chose different structures for their work groups. In general, work groups were structured in the same way as the plan's structure. Another characteristic of work groups is that they tend to meet more frequently than the full partnership—whether in person, by telephone, or a combination. Sometimes work groups contained members who were not part of the full partnership; this was particularly true where members of the full partnership were mandated by law as in North Carolina. In this case, work group membership was expanded to include members and organizations who were not legislatively eligible to sit on the full partnership. And work groups can evolve. They also may establish subcommittees to address specific needs, such as looking at a particular issue for a cancer site (a tobacco prevention subcommittee within a lung cancer work group) or a particular cancer site within a crosscutting issue or stage of prevention (a breast cancer subcommittee within an early detection work

group). Frequently, planners see the need to add or change work groups during the planning process, or when the plan is implemented.

Options for organizing work groups

- Maine and Utah chose to organize their work groups by the continuum of care—primary prevention, early detection, treatment, and rehabilitation and palliation/quality of life.
- North Carolina added site-specific subcommittees to the work groups on risk factors and continuum of care. Later, the state added an evaluation work group.
- Michigan began with site-specific work groups but later added groups to explore primary prevention and systems change issues that crosscut site-specific concerns.
- Illinois chose crosscutting issues—policy and infrastructure, public education and awareness, quality assurance (later titled Cancer Care Assessment), and data and surveillance—for its work groups. After completing its Action Plan, the work groups were reconfigured as action groups and were responsible for developing and monitoring work plans to implement priority strategies. Planners also added a Funding and Resource Action Group to develop funding resources.
- Kansas decided on a dual work group structure. Partnership members first split into cancer site-specific work groups—breast, cervical, skin, lung, prostate, and colorectal. They then added two crosscutting workgroups—crosscultural competency and rehabilitation and pain control—with the possibility of others in the future.

6.1.8 Assess partner satisfaction

Staff and leadership need to be attentive to the comprehensive cancer control partnership to determine if partners are satisfied with their level of input or with the process as a whole. This attention to the welfare of the partnership can help to alleviate small problems or avoid bigger ones, such as those associated with concerns over turf or dissatisfaction with level of participation. It also provides a way to acknowledge benefits that partners are finding through participation such as opportunities to work with colleagues from different kinds of organizations. Several ways to assess satisfaction include such simple methods as calling members who do not attend meetings and evaluation forms at the end of meetings or mailing them to partners at

regular intervals (every 6 months) (See Tool #21—Member Satisfaction Questionnaire). "Exit interviews" can be conducted with outgoing members of the partnership.

In Illinois, the Planning Coordinator made it a point to telephone members who did not attend meetings. This process served several purposes. First, it showed members that their presence was missed. It also updated them on what had transpired and preserved valuable time for the next meeting. Finally, this strategy helped identify any problems or issues with participation at an early point in time. Illinois also conducted a formal survey of its partnership at the end of the planning phase before embarking on implementation. The survey results were then compiled with graphs and charts and shared with the partnership (See Tool #21—Member Satisfaction Questionnaire).

6.1.9 Develop ways for new members to join and non-members to provide input

As the planning process unfolds, the need for additional input from underrepresented populations, from experts in particular fields, or from new members who might generate additional enthusiasm may become apparent. Those states and organizations with formal by-laws may need to amend them to add new members. Also, as the plan moves towards completion and implementation, calling on stakeholders or experts to provide specific guidance or input may be necessary. This step could involve working with fundraisers or sending the plan to medical or public health leaders to review specific sections. The point is that while it is necessary to have a dedicated group of partners with a shared sense of purpose, the partnership itself can suffer if allowed to grow static. Additionally, the needs of the initiative change over time and will likely require changes in membership, and possibly leadership. New members will benefit from a formal orientation, whether a face-to-face meeting with a member of the core planning team or an introductory letter with a packet of materials denoting the current status of the partnership.

In North Carolina, the state legislature set the by-laws that governed the number and types of members that were to be in its partnership. Yet, the input of additional medical and public health professionals, patient advocates, and consumers was valued, so many people participated in meetings as nonvoting members and joined work groups. Sections of the plan were sent for review to experts

within the state and elsewhere. During implementation of the Plan, the need for more voting members became apparent, particularly consumers. The partnership's enabling legislation was changed to allow this to occur. In all likelihood, the participation of several legislators as active voting members in the partnership helped smooth this change.

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Section 7—Assess and Address Cancer Burden

Nationally, cancer incidence, morbidity, and mortality remain high, and disparities in access to care, quality of care and outcomes persist despite efforts on many fronts to address them. In the early months of consensus building by various federal, state, and local agencies on the need for and purpose of comprehensive cancer control, stakeholders, led by CDC, discussed the need for additional elements, or building blocks, that would support efforts of a partnership to assess and then address the cancer burden. These building blocks, when joined together, increase the ability of a comprehensive cancer control planning body to meet the challenge of lessening the impact of cancer on individuals, families, and communities. Assessing and addressing cancer burden remains the crux of a meaningful comprehensive cancer control program, however is augmented by the other building blocks.

The *objective* for "assess and address cancer burden" is

> Reduce the overall morbidity and mortality from cancer and reduce the disparities in cancer burden among subpopulations.

The *planning outcome* that results from meeting this objective is

> Priority areas for cancer prevention and control are identified and prioritized.

As the comprehensive cancer control plan is implemented and the comprehensive process becomes institutionalized, additional outcomes are expected. Knowledge, attitudes, and behaviors related to cancer control will improve among consumers and providers, as will the health care system's ability to address cancer prevention and effectively meet the needs of those affected by the disease. Over time, this will lead to decreased incidence, morbidity, and mortality from cancer, as well as reductions in disparities among subpopulations.

7.1 Activities to Assess and Address the Cancer Burden

7.1.1 Organize partnership around areas of interest

Organizing the partnership into work groups has proven crucial for effectively carrying out planning and implementation activities. Work groups reflect the approach that the partnership is taking to develop a plan to alleviate the burden of cancer in the state, whether it focuses on specific cancer sites, cancer-related issues, or some other configuration. Because the work groups are undertaking primary responsibility for researching specific aspects of the cancer burden and recommending strategies to address them, the organization of the plan will likely mirror the structure of the work groups themselves.

In Kansas, the partnership developed an ambitious strategy for organizing itself into work groups. First, work groups were formed around specific cancer sites (breast, cervical, lung, prostate, skin, and colorectal) because the groups found it was easier to obtain data by type of cancer. Then, they regrouped according to level of prevention or care. Finally, the work groups reconfigured again according to crosscutting issues such as access to care. Once the work groups began to develop measurable objectives for specific cancer sites, the staff questioned the wisdom of regrouping. As they looked towards mobilizing support for implementation, they realized that legislators would respond better to cancer sites than to issues. At the same time, the objective-setting process revealed that some crosscutting issues required immediate attention. Therefore, two work groups were simply added to those already in place – cross-cultural competency and rehabilitation and palliation.

7.1.2 Determine critical areas of burden and high-risk populations

This activity is crucial to *assessing* the cancer burden. The purpose of data compilation and analysis during the early stages of planning is to answer key questions about the cancer

situation in the state. Some key questions are

- What are the most common or preventable forms of cancer in the state?
  - Consider incidence rates for various cancers by site or type (lung, breast, cervical, skin, prostate).
- What other forms of cancer are of concern to the population?
  - Consider whether or not to include lymphoma, leukemia, childhood cancers, or others, perhaps within crosscutting issues.
- Whom does each type of cancer affect?
  - Consider race, ethnicity, socioeconomic status, age, gender, and the potential for disparities.
- Where is cancer incidence high?
  - Look at individual counties, cities, or other administrative units that make sense for this state.
  - Look at urban/rural distinctions.
  - Look at stages at which cancer is diagnosed.
- Where are services located?
  - Look at distribution of accredited cancer centers.
  - Look at distribution of other services such as mammography, transportation, social services, etc.
- What are the major risk factors for each type of cancer?
  - Look at risk factor by population group (tobacco use among teenagers, physical activity at different age cohorts).
  - Although most cancer occurs in average-risk populations, understand that attention must also be paid to high-risk, underserved populations.
- What major crosscutting issues need to be considered, and who can champion them?
  - Consider access to care, palliation, cost, special populations, cultural competency, or other issues developed by partners.

Stakeholders have pointed out that the more focus placed on particular priority populations rather than large heterogeneous groups, the greater the chance that strategies will be appropriate. The core planning group should be sure to supply data early to the partnership so the partnership does not spend its time tracking down important and necessary information. The

activity of determining high-risk populations and persistent access problems may be carried out in work groups, or information may be presented to partnership members by staff and other experts (See Tools #16 and 19—Guide to Developing Issue Statements and Data Maps for Communicating Information to Stakeholders and Communities). Clearly, the activities conducted under Use Data and Research (Section 5) support this activity.

Furthermore, when data on the cancer burden in different areas and among priority populations are communicated clearly and concisely, they help to mobilize support for ways of addressing this burden.

Kentucky planners used information from the Kentucky Cancer Registry, Healthy Kentuckians 2000, Healthy People 2010, the Behavioral Risk Factor Surveillance System (BRFSS), tobacco databases, and Medicare data on the use of mammography to create charts and maps that show the incidence and mortality of the six highest cancers in Kentucky. Using these six cancers, the staff developed spreadsheets that showed trends for the state and the nation. The selection of cancer sites was based on "what was costing us most"—both in terms of the disease burden in the state and the economic burden of the disease. The use of colorful but simple graphics helped to promote buy-in from legislators and from community-based partners working through District Cancer Councils. (See Tool #19—Data Maps for Communicating Information to Stakeholders and Communities)

7.1.3 Assess gaps in strategies already in place

This activity is likely to be conducted in work groups. Although formal surveys to inventory current resources, services, and facilities may yield the best information (See Tool #6—Cancer Resource Inventory Form), partners can use published information, such as resource directories to develop an assessment of what is already in place, and what is missing. Assessing the *quality* of existing data is ideal but this may prove unrealistic early in the planning cycle. Partnerships may need to limit themselves to assessing the *presence* and *absence* of this information. Still, any available evaluation data would certainly strengthen decisions that need to be made as to what is already available to the public, what is available but needs to be modified or strengthened, and what needs to be created anew.

In Illinois, the Public Education and Awareness Work Group created a Resource Inventory Form (See Tool #6—Cancer Resource Inventory Form) and distributed it to all partnership members. The form asked for any public education materials the partnership organizations had developed. The form focused on lesser known resources rather than on those available in an organization's published catalogue. Results were distributed to the partnership to help determine which materials could be disseminated more broadly and what materials may have to be created in the future. The partnership also sponsored a needs assessment survey (See Tool #8—Local Health Department Needs Survey) for local health department administrators and health education staff to learn about support needed from the American Cancer Society.

7.1.4 Create measurable goals and objectives for the plan.

The goals and objectives developed from the initial vision form the basis of any comprehensive planning document. Objectives are developed on the basis of sound data, experience, and knowledge. When objectives are tied to data, they are linked to a real need, rather than to an individual agenda or bias. Often, work groups that have been examining data related to their particular area of focus (risk factor, site, or issue) have been doing so with a particular goal in mind. For example, if a work group seeks to prevent lung cancer in a state as its broad goal, it may then develop objectives linked to data that are related to evidence of tobacco use in the state. For each objective, partners can develop a statement showing how it is linked to data or what data would be needed to measure progress toward meeting the objective.

Using measurable goals and objectives provides a way to evaluate the impact of the plan on the populations that it is addressing. Sometimes important issues require a goal or even an objective that cannot yet be measured. In such cases, it is important to consider how a change will be demonstrated once this objective is met.

Measures are important because they provide evidence of what comprehensive cancer control is accomplishing. Evidence of success helps to ensure that funders and other stakeholders will value the **plan** and support it in the future. Evidence of the need for improvement will help to strengthen implementation and future iterations of the **plan**.

The reader may want to review the discussion in Section 2 regarding criteria for well-formulated goals and objectives. The goal can be written as a general statement, and the objective should be written so that it incorporates a way of measuring its own attainment. If appropriate, they should meet the SMART criteria—the objectives are Specific, Measurable, Attainable, Realistic, and Time-phased (See Tool #17—Objectives Litmus Test)—and in such a way that meeting these goals and objectives answer the questions:

Where did we come from?

Where are we going?

How far do we need to go?

How long will it take?

Each of Maine's five work groups created one or more issue statement (See Tools #16—Guide to Developing Issue Statements) from which they developed goals and objectives. Planning coordinators provided guidance on definitions and descriptions of the plan components to ensure a common language for planning. The work group members then presented their goals and objectives to the partnership as a whole. Partnership members provided feedback that work groups then incorporated into their revisions. Work group co-chairs described the process of presenting their work to the full partnership as a process of "mutual education"—all members learned about issues the work group experts considered important, but the work group members also learned how to defend their priorities to nonexperts. The partnership's Coordinating Committee also decided to add several overarching goals in the areas of data, access to care, quality of care, and advocacy.

7.1.5 Identify possible intervention strategies

Once goals and objectives have been developed, creating strategies to meet them is possible. This process should also be evidence driven and should use the scientific literature and the collective experience of the group to look closely at what the options are and how good those options are. The planning process needs to address such questions as:

What strategies have worked well in the past?

Look at strategies that have been employed in other states and organizations.

Examine evaluation data that are available or published intervention research.

Refer to The Guide to Community Preventive Services.

What strategies that have been tried in the past do not work well?

Examine evaluation data for clues as to why the strategies have not worked well.

What new strategies should be considered?

Look at scientific evidence for the effectiveness of each strategy being considered.

Who is likely to support each kind of strategy?

Consider "nontraditional partners" such as faith-based organizations, local businesses, or groups of small businesses.

What data are needed that are not yet available?

Prevalence data for specific cancer sites are often unavailable, as are data on cost.

Data may need to be broken down by smaller geographic units than currently available.

Consider whether these data are necessary for planning or can be collected as part of the implementation of the **plan**.

What data are needed to effectively evaluate proposed intervention strategies?

What other research or scientific reports are needed that are not yet available?

Consider whether each strategy has scientific backing for its effectiveness.

What other considerations need to be made?

Consider the political or policy implications of decisions made for the plan.

For the partnership to make a sound decision as to what should, or should not, be included in the plan, participants must be familiar with state-of-the-art medical and behavioral science. In this way, champions of a particular objective and strategy can explain their reasoning to the larger group. During this step of the process, experts within or external to the partnership can prove extremely valuable. They can review research reports on appropriate strategies for meeting objectives under consideration or simply answer questions and help interpret them for participants. Examples include reports on the outcomes of interventions in risk factor counseling, health education, or community interventions, as well as research reports that will help staff and

members decide on the efficacy and cost effectiveness of strategies under consideration. Even so, uncovering all the research that is desirable at this time may not be possible; so again, undertaking further research may need to be included within the plan as a strategy clearly linked to a goal and objective.

In reality, this segment of cancer planning is a highly iterative process. Sometimes planners discover that the objectives are really strategies and the strategies may be better framed as objectives or even as indicators or activities. At other times, favorite strategies do not really meet a desired objective and either the objective or strategy needs to be thought through again. Still, as a beginning point participants should brainstorm and research as many strategies as are reasonable within the planning time frame. Then, the rationale for each in light of the objectives can be developed.

The Task Force on Community Preventive Services provides recommendations for evidence-based public health interventions designed to promote health, prevent disease, injury, disability and premature death as well as exposure to environmental hazards. Chapters on tobacco control and physical activity have been published and are available on line. Other cancer-related chapters are in development. The cancer chapter will address interventions in communities and health care systems that promote screening for breast, cervical, skin, and colorectal cancer. It will also have information about effective interventions to reduce the risk of skin cancer and promote informed decisions about prostate cancer screening. More information about the Guide to Community Preventive Services can be found at www.thecommunityguide.org.

Sometimes a state may have done a great deal of planning within particular issues or categorical areas, and creating a new set of goals and objectives around these areas could lead to redundancy. For example, the Kentucky planning effort for comprehensive cancer control integrated the goals and objectives of cancer stakeholders by incorporating the work done in categorical or issue-oriented planning efforts. Members looked closely at other plans in the state to integrate those goals and objectives into the cancer plan. Those plans included the Kentucky Breast Cancer Action Plan, American Cancer Society priorities, Journey's End (on end-of-life-issues), and Educating Providers about End-of-Life Care. The core team then looked at the feedback from a Survey of Needs. This survey indicated what stakeholders throughout Kentucky saw as the most pressing issues and what they would like to see done about these issues—as a way to prioritize potential strategies for the Plan. Recommendations in the comprehensive cancer control plan focused on cancer sites, (lung cancer), priorities concentrated on priority populations (youth), and strategies addressed methods to achieve the priorities (restricting access to tobacco).

7.1.6 Prioritize goals, objectives and strategies

The prioritization process may be the most iterative aspect of comprehensive cancer control planning. This is where some objectives and strategies may simply be dismissed or where some members may argue forcefully for favorites although others are not so sure of the wisdom of including them. The important point is that to keep the process on track, staff and leadership must develop a fair approach that is inclusive and time-bound, but based on objective, agreed-upon criteria. Typically, more than 100 objectives (with or without strategies) may need to be winnowed down to a dozen. Minority reports may be added to the plan, or several member organizations may decide to independently support a favorite strategy that is not adopted for the state as a whole. Such variations in the prioritizing process are valid as long as the process itself remains inclusive and not fragmented.

Some strategies for effective priority-setting activities include

Use a consensus development process with the full partnership.

A popular approach is to place sheets of newsprint around the meeting room. Each sheet contains the objectives and strategies (below the goal statements) for each work group. The partners walk from sheet to sheet and vote for the objectives and strategies.

A committee of representatives from each work group (work group chairs and facilitators), executive committee, or steering committee, prioritizes the objectives and strategies.

Usually, the committee needs to go back to the full partnership for its approval of the committee's decisions.

A written ballot is sent out to partnership members and then staff compile the results (See Tool #18—Ballot for Goals and Objectives Selection).

Staff send a ballot to partnership members that contains the objectives and strategies (grouped by goals) and ask them to rank the goals. The compiled results are then reported to the partnership.

Staff rank the objectives and strategies.

Staff then present their results to the partnership or to the executive or steering committee for consent.

A combination of methods.

One method is used, such as a mail-in ballot or steering committee meeting, to obtain a manageable number of objectives and strategies. These objectives and strategies are presented to the partners who then rank them until the desired number remains.

In Illinois the prioritization process encompassed the following steps:

1. The work groups defined and ranked the priorities developed for each work group.
2. The partnership met and collapsed the 20 priorities developed by the work groups into seven major priorities for the entire partnership. Consensus among members was required.
3. The work groups reexamined the collapsed priorities to ensure that the overarching priorities did not change the intent of individual priorities. Through a process of regrouping, Illinois collapsed the seven priorities into six priorities.
4. The work groups developed strategies to address each of its original priorities. A priority matrix was used to create a one-page display of priorities developed by the individual work groups.
5. The work groups presented strategies to the entire partnership, which prioritized them by grouping them according to those that could achieve the six overarching priorities.

7.1.7 Identify organizations to implement plan strategies

This step is one of the most important activities of planning. Much work can be wasted if no organization is identified to implement certain strategies. Some states, such as Arkansas, were proactive, requesting a commitment to help implement the plan at the first partnership meeting. Still, at some point in the process, obtaining commitments from partners to support specific strategies is necessary.

In Maine, a single goal was often associated with several objectives, and each objective was associated with multiple strategies for achieving it. Maine asked member organizations to sign up as an implementing organization for specific goals and their related objectives, rather than for individual strategies. As part of its prioritization process, work groups presented revised and prioritized goals and objectives to the partnership. Priority goals and objectives had asterisks (*) placed next to them indicating that the experts in that area considered them highly important. The partnership members then selected the goals and objectives to be included in the plan by voting and demonstrated willingness to support implementation by "signing up" for one or more (See Tool #18—Ballot for Goals and Objectives Selection). To make the final "cut" to be included in the plan, each goal and objective had to have at least one organization "sign up." The organizations that signed up for a given goal/objective were then put in contact with the work group responsible for it so that they could participate in the strategizing portion of the planning process, which would involve prioritizing strategies for implementation.

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Section 8—Conduct Evaluation

The structure of this section is somewhat different from that of the preceding building block sections. Evaluation cuts across all building blocks and through the entire planning process. However, evaluation is a building block in its own right, with its own sequence of steps leading to a plan that contains a strategy for measuring the implementation of the plan. Evaluation plays an integral role throughout the planning process, providing a means of informing and assessing the planning process itself and the initiative as a whole. Thus, evaluation occurs both during and after development of the comprehensive cancer control plan. Furthermore, evaluation has presented challenges for practitioners of comprehensive cancer control and warrants a more in-depth treatment.

This section begins with a discussion of the importance of evaluation for the comprehensive cancer planning process and is followed by an acknowledgement of some of the challenges to incorporating evaluation. The remainder of the section then recommends specific means to overcome evaluation challenges and to effectively use evaluation to support the planning process while preparing for implementation of the plan.

The *objective* for the "Conduct Evaluation" building block is

> Develop a strategy for assessing both process and outcomes associated with comprehensive cancer control planning and implementation.

The planning *outcome* associated with meeting this objective is

> A strategy for assessing the planning process, monitoring implementation, and measuring outcomes is in place.

As a result of the evaluation-related activities (shaded) in the building block model, when the plan is implemented (1) the implemented strategies are evaluated as is the implementation process; and (2) evaluation data are used appropriately for accountability and program improvement purposes. When the comprehensive cancer control process is institutionalized, then evaluation data become routinely and appropriately incorporated into a cyclical decision-making process along with other forms of evidence.

The process of creating a vision, as described in Section 2, and the evaluation-related activities outlined in the Buildings Blocks for Comprehensive Cancer Control Planning Model (Figure 1.2) help ensure that evaluation is feasible and useful during the planning process and thereafter. Developing a vision during the early stages of planning ensures that the effort has a clear, agreed-upon direction and that both the process itself and the plan produced by the process can be evaluated. The building block model can effectively be used to support what evaluators refer to as a program-centered approach to evaluation. The shaded cells in the model that represent evaluation activities appear not only in the "Conduct Evaluation" building block but are interspersed throughout the other building blocks as well.

8.1 Why Do Evaluation as Part of Comprehensive Cancer Planning?

Many public health professionals express concern over the lack of information available on "effective" public health programs. The comprehensive approach to cancer prevention and control stresses the critical importance of evidence-based decision-making, and evaluation is one of several types of evidence supporting the comprehensive approach. Other kinds of evidence used in planning are summarized in Table 5.1 in Section 5.

Evaluation can provide critical support for the development and implementation of a comprehensive cancer control plan. Evaluation has its uses throughout the comprehensive planning process. Evaluation activities that are conducted early in the planning process can inform the process; those activities conducted along the way help ensure that everything is unfolding according to plan and determine whether midcourse corrections are necessary. Those evaluations that are conducted at the end of the planning process can be used to judge success and inform future planning.

The process of evaluation also can be helpful at two levels. At the initiation level, evaluation can help answer the questions, "Is the comprehensive cancer control process working well?" and "Are the partnership's overarching goals and objectives being achieved?" At the implementation level, evaluation can help answer questions such as, "Are the strategies proposed in the plan being implemented?" and "Are the outcomes anticipated by the partnership being achieved?"

During the planning phase, a sound evaluation approach enables planners to accomplish such critical tasks a:

Conducting assessment activities to guide various key stages of the planning process.

Determining whether the process is maintaining its focus and staying on course, while also providing opportunities for midcourse correction.

Providing information on results of the process to those on whose support the credibility and longevity of the process depend, such as legislators and other decision-makers.

Writing measurable planning objectives and devising means to measure the extent to which implemented strategies succeed in achieving objectives.

Note that all of the above uses of evaluation during the planning phase relate principally to evaluation of the comprehensive cancer control initiative, with the exception of the last bulleted item. Actually conducting an evaluation to determine whether or not individual strategies from the plan are being successfully implemented and whether anticipated health outcomes are being achieved lies outside of the planning phase. Obviously, this type of evaluation cannot be conducted until one or more strategies have been implemented and are beginning to produce results. However, much of the work done during the planning phase ensures that it will be possible to conduct an outcome evaluation of the plan implementation, a subject that will be discussed in Section 10.

8.2 Activities to Conduct Evaluation

The program-centered approach to evaluation presented in this section provides an overall strategy for overcoming challenges to evaluating a complex initiative such as comprehensive cancer control. This approach involves: (1) a set of evaluation activities conducted during the planning phase as outlined in the "Conduct Evaluation" building block, and (2) a set of evaluation-related activities conducted during the planning phase to support work on the other five building blocks.

8.2.1 Evaluation Activities Conducted during the Planning Phase—The Conduct Evaluation Building Block

The ***Conduct Evaluation*** building block contains a set of suggested activities in roughly chronological order that might reasonably be undertaken by comprehensive cancer control practitioners to support the development and implementation of an evaluation strategy. Each of these activities is discussed in turn below.

Identify resources and staff for evaluation

Early in the planning process some consideration should be given to identifying staff and other resources for evaluation (See Tool #1—Self-Assessment of Capacity for Comprehensive Cancer Control Planning). Even if it is unreasonable for the planning coordinator to assume both evaluation and planning responsibilities, and the core team lacks all necessary skills, evaluation expertise can still be found, and need not be expensive. Some state health agencies have in-house evaluators who may be interested in evaluating a working collaborative, such as a comprehensive cancer control partnership. Local colleges and universities may offer evaluation degrees or evaluation coursework within a health or social science degree and may welcome the opportunity for their students to gain real-life evaluation experience. Partner organizations may be willing to share in-house evaluation expertise as an in-kind contribution.

Define planning evaluation questions

Evaluators often use a set of evaluation questions to structure their evaluation strategies. Framing data collection activities as the means to answer questions of interest to the initiative, its coordinators, and its participants is a way to ensure that any evaluation data collected can be used to provide important and useful information. The questions developed should concern issues that planners and their partners truly need to know about in order to proceed effectively with the process.

The difficulty in developing questions for an initiative like comprehensive cancer control is not devising the questions, but rather ensuring that those selected are the right questions and represent *a small enough number* that they can be readily answered within available evaluation resources. A long list of questions that is not prioritized in any way can lead to a diffuse and overly ambitious evaluation plan. Developing a hierarchy of questions is useful in this regard.

That is, consider formulating a small number of key questions (no more than four or five) and grouping under them additional related questions which, when answered, will contribute to answering the key questions. This approach helps ensure that a concentrated focus for the evaluation is maintained.

Recognition that evaluation questions will likely change as the initiative evolves over time is also important. The burning questions during planning are different from those during implementation. Because the model incorporates a tested theory of how the initiative is expected to progress, using the building block model as a conceptual framework for developing evaluation questions ensures that planners consider the evolutionary aspect of comprehensive cancer control. Designing an evaluation strategy that acknowledges the evolutionary nature of comprehensive cancer control will be discussed further in Section 10 (Looking Ahead).

Examples of evaluation questions that could be asked at different stages in evaluation of the comprehensive cancer control initiative are shown in Table 8.1.

Table 8.1 Sample Evaluation Questions

Evaluation Level	Evaluation Questions
CCC Initiative Process Evaluation	Is the comprehensive cancer control process working well?
	Are meetings regularly attended?
	Are members satisfied with the process?
	Are planning tasks being accomplished and are planning products being produced in a timely manner?
CCC Initiative Outcome Evaluation	Are the partnership's overarching goals and objectives being achieved?
	Is infrastructure for cancer control being enhanced?
	Is support for the initiative being mobilized?
	Are data and research being utilized?
	Are partnerships being built?
	Is the cancer burden being assessed? Addressed?
	Is evaluation of planning process and outcomes being conducted?
CCC Plan Process Evaluation	Are strategies proposed in the plan being implemented?
	Are knowledge gaps being addressed through surveillance and research?
	Are the health systems issues impacting each cancer prevention and control intervention strategy being addressed?
	Are interventions being delivered— • To subpopulations with high risk and high burden? • In a culturally appropriate manner? • In a timely manner? • In a cost effective manner?
	Are implementation difficulties being successfully overcome?
CCC Plan Outcome Evaluation	Are the health outcomes anticipated by the partnership for each strategy being achieved?
	Has the baseline problem status identified by partners improved?
	Over time, has incidence, morbidity, and mortality from cancer decreased?
	Over time, are health disparities relating to cancer among subpopulations reduced?

Besides considering these evaluation questions, the adequacy of the evaluation should be considered. For example, Will the evaluation and data collection allow for a complete and appropriate evaluation of your project? Is the data being used to evaluate the plan or intervention strategy sufficient to provide a truly effective evaluation?

Document the planning process

Earlier, the point was made that expecting the planning coordinator or members of the core team to shoulder heavy evaluation responsibilities was unreasonable. This is not to say, however, that these individuals will not be involved in a key aspect of evaluation—namely, documenting the planning process.

Often careful documentation supports programmatic activities as well as evaluation activities. Even if there seems to be little time to reflect about the comprehensive cancer planning process while it is under way, a simple strategy can be put in place to systematically archive planning tools and products (timelines, minutes) as they are developed. This strategy facilitates locating and retrieving such materials if they are needed for informational purposes, and helps to prepare for an evaluation of the planning process that may occur at a later point in time.

Identify emerging challenges, solutions, and outcomes of the planning process

Many planning coordinators and core team members view themselves chiefly as process facilitators and problem-solvers. Ongoing monitoring to detect and document emerging challenges, solutions, and outcomes of the planning process is an important function for evaluation that also aids facilitation and problem-solving. Such monitoring also is clearly in line with a utilization-focused, program-centered approach to evaluation that serves programmatic improvement, facilitates mid-course corrections, and generates information immediately useful to program staff.

Tip. Consider compiling a formal record of some of the partnership's early accomplishments. Sharing information on perceived benefits with partners is a simple way to provide regular feedback to members on how the process is going and what the partnership is accomplishing along the way. Besides collecting this information for evaluation purposes, a list of benefits being derived from the initiative can also be useful in mobilizing support.

One means of systematically approaching this type of evaluation activity is to encourage core team members to identify challenges before they become serious problems so that the staff (and perhaps key partners) can jointly brainstorm about possible solutions during core or even expanded team meetings. Consider using a simple matrix to document these emerging challenges and record solutions as they are devised.

Note that whenever a solution is successful in addressing a given challenge, it then represents key preliminary outcomes of the planning process, such as evidence of enhanced infrastructure, a stronger partnership, increased use of data and research in decision-making, and improved support for cancer prevention and control. Because health outcomes (such as decreases in cancer morbidity and mortality or reduction of disparities between subpopulations) will only be achievable in the long term, documenting intermediate positive outcomes of the planning process is particularly important. Table 8.2 provides a sample matrix of challenges encountered and solutions devised by some of the model planning states during their comprehensive cancer control initiatives.

Table 8.2 Challenges Encountered and Solutions Devised During Comprehensive Cancer Control Planning

Challenge	Solution
Enhance Infrastructure	
Kansas: Staffing shortages and relocation made it difficult to dedicate staff to the CCC planning effort.	In the absence of a dedicated staff person, the state adopted a team approach by using several core staff to actively plan the general meetings and additional staff to facilitate the work groups. A graduate intern provided help during the period when the work groups developed preliminary objectives. Nevertheless, the timeline was more protracted than hoped because of the lack of dedicated staff. A part-time coordinator worked closely with health department staff and partners to develop the plan objectives in work groups. An outside facilitator also helped to initiate the partnership.
Mobilize Support	
Illinois: The chronic disease division had no funding for cancer-related activities. Even the largest federally funded cancer program (the Breast and Cervical Cancer Program) was located outside the division.	The division made use of Prevention Block Grant funds to initiate CCC. Interns were used to supplement existing staff. Unobligated Breast and Cervical Cancer Program funds were used for printing the plan and handling related expenses
Utilize Data/Research	
Arkansas: During the very earliest stages of the CCC planning effort, the core team recognized that much needed to be done to ensure that adequate data would be available to support the process. The central cancer registry was not operating at peak effectiveness, and was critically short on necessary staff.	Concerted efforts were made to enhance the Arkansas Central Cancer Registry, including ensuring adequate state funding, establishing consistent leadership, filling empty staff positions, and achieving adequate performance measures (completeness of data reporting). These efforts were aided by advocates within the private sector and by technical assistance from another model planning state (Kentucky). In addition, there are current efforts to build linkages between cancer registry data and data available through the Vital Statistics office, expanding the breadth and depth of useful data for CCC planning.
Build Partnerships	
Maine: Staff needed to build ownership of Consortium (partnership) members in the initiative.	An organizational structure was created that provided many opportunities for members to become involved at different levels. Leadership (Consortium or work group co-chair), steering (Coordinating Committee), feedback on work group products and overall priority-setting (Consortium membership) were addressed. Work group co-chairs became a "leadership team" through regular meetings of the co-chairs (as a group) with the Planning Coordinator to discuss mutual issues and concerns. The entire Consortium was included in key decisions by providing members with a range of options presented systematically (in a matrix outlining pros and cons) that allowed a discussion of the options (often in small groups) and then a consensus decision by the group.
Assess/Address Cancer Burden	
Kentucky: CCC team recognized a need to evaluate the plan	CCC plan objectives were modeled after Healthy People 2010 and Healthy Kentuckians 2010 objectives. Objectives were made measurable.

Most planning coordinators, core team members, and partnership members can readily provide individual anecdotal examples of benefits achieved through a comprehensive cancer control planning process. Table 8.3 provides a sample list of benefits experienced by some of the model planning states during their comprehensive cancer control initiatives.

Create an evaluation plan for implementation

The planning coordinator and core team members will create a good foundation for a subsequent evaluation of plan implementation by doing as much as possible during the planning process to ensure that the comprehensive cancer control plan is as assessable as possible. Helping work group members identify available data sources and providing guidance and technical assistance on the formulation of goals, objectives, and strategies accomplish this. Additional aspects of plan implementation that need to be considered in developing an evaluation plan include:

Remember Although every attempt should be made to ensure that the CCC plan can be assessable, planners should nevertheless keep in mind that the SMART formula—Specific, Measurable, Attainable, Realistic, and Time-phased objectives described in Section 2 and elsewhere in this guidance document—represents a guideline, not a template to be strictly adhered to. Work group members' sense of pride and ownership in the plan and their belief that the plan represents something important and doable is ultimately of more value for implementation than perfectly formulated goals and objectives. The planning coordinator and core team members must guide the process without becoming rigid about SMART-"compliance."

Who will monitor implementation? The coordinating agency or a designated partner needs to monitor whether strategies are being implemented as planned and, if not, determine why not.

How will implementation be monitored? A state or organization may choose to use a simple database with fields for names of the objective, associated strategies, implementing organization, and date of completion.

For which of the strategies will full-fledged implementation assessments be conducted and for which will a simple "accomplished? yes/no" suffice? Funds for full-scale process and outcome evaluation of each strategy will likely not be available. Therefore, an evaluation work group, the core team, or some other responsible group within the partnership should decide on a limited number of strategies that can

Table 8.3 Benefits Attributable to the Comprehensive Cancer Control (CCC) Process

Benefit	Parties Involved	Comments
		Benefits Related to Enhancing Infrastructure
Illinois: Increased staff capacity through use of public interns.	Universities Interns Illinois Department of Public Health (IDPH)	MPH interns from local universities contributed specific skills at relatively low cost. Substantive, concrete tasks included developing a CCC web page, producing county-specific cancer data profiles, supporting work/action groups, and designing an evaluation strategy for the initiative. Two interns received jobs at the health department (one in CCC, one in the Division of Communications), and one went on to an internship at NCI.
		Benefits Relating to Mobilizing Support
Maine: Template for planning within Maine and within the New England region.	Bureau of Health (BOH) Consortium members	Other programs in the Bureau of Health are looking to the CCC Consortium to develop a model they can use for their own statewide planning processes, (Nutrition and Five-A-Day). The comprehensive cancer control process, which brings varied partners into a statewide coalition, can serve as a model process for other diseases and issues. At the state public health association's annual meeting, a major prevention summit, BOH staff will present on the CCC process as a model for other initiatives. The regional ACS office is also looking to Maine as a model for state-level and regional-level collaboration on cancer control.
		Benefits Relating to Using Data and Research
Arkansas: Enhancement of the Arkansas Central Cancer Registry.	Arkansas Department of Health (ADH), Arkansas Central Cancer Registry, Arkansas Breast Cancer Program	Early efforts to initiate the CCC planning process contributed to the development and enhancement of the Arkansas Central Cancer Registry. ADH staff recognized that CCC planning, implementation, and evaluation would depend on the state's central cancer registry. Thus, concerted efforts were made to enhance the registry so that it would be operating as near to full capacity as possible by the time planning was underway in earnest, a goal that has been accomplished. In summary, CCC in Arkansas served as a catalyst for enhancing the Arkansas Central Cancer Registry.
		Benefits Relating to Building Partnerships
Utah: Building relationships with other organizations.	Utah Department of Health (UDH) and key partners	Through CCC planning, the UDH has begun to build stronger relationships with Huntsman Cancer Institute, the Cancer Registry, and other organizations. Partner organizations appreciate the opportunity to network with other cancer stakeholders across the state. Partners have begun to request contact lists to share information and have asked the planning coordinator to share information with the members. The core staff must to determine how to handle this influx of information.
		Benefits Relating to Assessing/Addressing the Cancer Burden
Kansas: Early implementation of a strategy.	Staff and partners of the Kansas Department of Health and Environment	Several questions were added to the BRFSS to provide baseline behavioral data on skin cancer, prostate cancer, colorectal cancer, and end-of-life issues.
		Benefits Relating to Conducting Evaluation
Kentucky: "Survey of Needs" identified stakeholder concerns across the state.	Kentucky Cancer Program, Stakeholders	The Survey of Needs was sent to 445 individuals throughout the state to help identify areas of concern around the state as a way to provide input on plan objectives.

receive full evaluation. These should be strategies that are likely to yield important new knowledge concerning the issue being addressed.

How will lessons learned about best practices and effective means of overcoming implementation difficulties be shared with members of the partnership and other stakeholders? This can be done through such means as (1) requiring periodic progress reports on individual strategies and sharing highlights through regular correspondence with partners or through providing summary updates at partnership meetings, (2) inviting those partners implementing strategies to present at partnership meetings, (3) sharing printouts from the implementation database, or (4) developing an implementation newsletter to which partners and planning staff contribute short articles.

8.2.2 Evaluation-Related Activities that Support Other (Nonevaluation) Building Blocks

Planners are often concerned about how to conduct evaluation while busy with the intensive, day-to-day activities associated with laying the groundwork for planning, maintaining the process, and writing a good comprehensive cancer control plan. Integrating evaluation activities with programmatic activities throughout the planning process is the best way to accomplish this. In the building block model (Figure 1.2), darker highlighted cells within each row suggest specific evaluation-related activities that can be integrated with the programmatic activities for those building blocks. Each of these activities was presented in detail under the section where the building block is described.

8.2.3 Ongoing Evaluation Activities that Generate Usable Data

As mentioned earlier, evaluation has uses throughout a comprehensive cancer control initiative. Evaluation activities conducted early can inform the planning process (formative evaluation). Those activities conducted along the way help ensure that everything is unfolding according to plan and determine whether midcourse corrections are necessary (process evaluation), and evaluation activities conducted at the end can be used to judge success and inform future planning (outcome evaluation). These three types of evaluation are discussed below in the context of developing a strategy for meaningful, ongoing evaluation of a comprehensive cancer control initiative.

Formative evaluation

Formative evaluation data, generally collected either before the comprehensive cancer control initiative begins or before it enters a new phase, can generate a steady flow of information for planning coordinators and their partners. Such data can be used to guide development of a comprehensive cancer control initiative and to support informed decision-making at key points in the process. The majority of the evaluation activities in the darker highlighted cells of the building block model (other than those in the ***Conduct Evaluation*** row) involve formative evaluation activities designed to gather information to help guide the initiative as it moves forward.

At least one activity for assessing formative needs is recommended for each of the building blocks in order to determine baseline status in each of the six areas and to identify where effort is need to improve the status quo. Five of these are described in Table 8.4.

Table 8.4 Formative Evaluation

Building Block	Formative Activity and Purpose
Enhance Infrastructure	*Assess infrastructure needs and capacity* by looking closely at infrastructure assets and barriers within the coordinating agency and among key stakeholders. This activity will help determine what is necessary to mount and sustain a comprehensive cancer control initiative.
Mobilize Support	*Assess current level of support* by considering the level of support available at baseline for cancer prevention and control activities (within the coordinating agency and beyond it). *Reassess partnership representation and coverage for implementation* to ensure that the mix of people and organizations comprising the partnership is appropriate and adequate to sustain the implementation of the plan.
Use Data and Research	*Assess data gaps* after work group members have already made some attempt to work with whatever data and research currently exist. The partnership can then develop an agenda to improve data availability in support of subsequent phases and later cycles of the planning process.
Build Partnerships	*Assess partner interest and capacity* to support member recruitment and orientation.
Assess/Address Cancer Burden	*Determine critical areas of burden and high-risk populations* to develop the initial focus of the initiative. This determination may guide development of the work group structure around specific cancer sites or risk factors, including structures to address subpopulations with unusually high cancer risk. *Assess gaps in strategies already in place* to guide and focus the strategy development process by providing information that can help avoid overlap and duplication of effort.

Process evaluation

Process evaluation data can be used to monitor and document an initiative, identify the need for midcourse corrections, and generally contribute to program improvement over time. The building block model provides a broad blueprint for activities that can be conducted to strengthen the comprehensive cancer planning process during each of its phases. Planners can devise means to assess whether these activities are occurring as expected (See Tools #2 and 3—Timeline for Planning Tasks and Chronology for Planning Activities). As such, the model can serve as the basis of an initiative-level process evaluation both during and after plan development.

Plan development phase. The Building Block Model for Comprehensive Cancer Control Planning represents a series of activities that practitioners must accomplish to move the initiative forward in each building block area. An initiative-level process evaluation can be structured easily to monitor whether these activities (or related activities) are occurring as planned.

Table 8.5 Process Evaluation Strategies and Data Sources to Document Ongoing Activities

Building Block	Activity/Process Evaluation Strategy (Data Source)
Enhance Infrastructure	*Coordinate and monitor process* Log of activities (See Tool #3—Chronology of Planning Activities). Database of members. Timeline of tasks (detailed timeline for planning staff and highlights for partners) (See Tool #2—Timeline for Planning Tasks) Minutes of meetings (both full partnership and work group meetings).
Mobilize Support	*Secure funds and in-kind resources for planning* List of resources used to support the process including source and description of each (See Tool #6—Cancer Resource Inventory Form)
Mobilize Support	*Publicize efforts of the partnership* Log of activities by planning staff and partners that contribute to improved visibility for the initiative. List date, activity, and nature of audience to which staff or partners participated, comments (including outcomes, such as new members joining or invitation to address a new group of stakeholders) (See Tool #3—Chronology of Planning Activities).
Utilize Data/Research	*Identify available data/research* Matrix of potential data sources to support evidence-based planning, including name of data source, location of data source, characteristics, and comments (See Tool #7—Data Resource Inventory Sheet).
Build Partnerships	*Assess partner satisfaction* Formal survey of members, current and past partners, to determine level of satisfaction, detect problem areas, and determine future direction (See Tool #21—Member Satisfaction Questionnaire). *Ad hoc* surveys of member satisfaction with meeting format. Log of telephone contact with members who miss meetings. Exit interviews with departing members. Notes of impromptu "interviews" with partners who call planning staff for various reasons.

Ad hoc process evaluation activities can also be used as a trouble-shooting mechanism, instituted when a particular problem is identified. For example, if attendance at meetings is declining, telephoning members who have missed meetings can serve several purposes—assuring the partners that their presence was missed, updating them on what has transpired to reduce their learning curve when they return, and detecting reasons for absence that may not be merely personal but symptomatic of a more general problem or problems within the partnership.

Implementation phase and beyond. One of the challenges to evaluating a complex initiative such as comprehensive cancer control is the fact that it is a dynamic process that evolves over time. Activities expected during the planning phase are different from those expected during implementation and beyond. In Section 10 (Looking Ahead), we will revisit the

subject of evaluation and consider how the Building Blocks for Comprehensive Cancer Control Planning Model can also support process evaluation of plan implementation and institutionalization of the planning process.

Outcome evaluation

Outcome evaluation can be used to market the initiative, mobilize support, and generate accountability data for legislators and other decision makers. Outcome evaluation can also help detect problems in the way the initiative is progressing. Like formative and process evaluation, evaluation of the outcomes of the initiative can also rely on the model provided by the Building Blocks for Comprehensive Cancer Control Planning.

Outcomes can be seen at three levels. They are (1) outcomes of planning, (2) outcomes associated with particular plan objectives and strategies (outcomes of implementation), and (3) outcomes associated with the institutionalization of the plan.

Evaluating planning outcomes. In Table 8.6, we review the planning outcomes associated with the various building blocks. The achievement of each planning outcome can be tracked through a simple log or through a column in the initiative work plan.

Table 8.6 Planning Outcomes by Building Block

Building Block	Planning Outcome
Enhance Infrastructure	• Management and administrative structures and procedures are developed. • Planning products are produced, disseminated, and archived.
Mobilize Support	• Partnership develops priorities for allocation of existing resources. • Gaps in resources and level of support identified.
Use Data and Research	• Planning and research data reviewed for needs assessment and strategy development. • Data/research gaps identified.
Build Partnerships	• Original members remain committed as new members join. • Partnership/subcommittee meetings held and attended.
Assess/Address the Cancer Burden	• Target, select, and prioritize areas for cancer prevention and control.
Conduct Evaluation	• A strategy for assessing planning process, monitoring implementation, and measuring outcomes is in place.

Outcomes associated with institutionalization. In this section, the focus has been on planning outcomes and on preparation for measuring implementation outcomes. However, these outcomes are rendered much more meaningful if something can eventually be said about the impact over time of the comprehensive cancer control initiative upon the burden of cancer in a particular state, territory, tribe or other jurisdiction. Several interventions may already have an impact on the burden of cancer in other geographic areas. To follow developments in this issue, please refer to The Guide to Community Preventive Services (www.thecommunityguide.org). This discussion is deferred to Section 10 (Looking Ahead).

8.3 Conclusion

Although the focus in the Conduct Evaluation building block is on preparing for plan implementation and developing an evaluation strategy that can be incorporated into the comprehensive cancer control plan, the philosophy continues to be that evaluation of the planning process provides feedback regarding the implementation of the plan and the institutionalization of the initiative. In Part III, comprehensive cancer control is examined as a process that occurs within a certain timeline and integrates the various building blocks throughout its life cycle.

The building block model is not meant to be strictly followed. It was developed from the experiences of six model planning states and six implementation programs and from information

in the literature, evaluations of other collaborative efforts, and input from a variety of stakeholders. Because environments differ greatly from one state to the next, numerous variations can be expected between the generic model and any subsequent individual implementations. These variations are not inherently "good" or "bad." A good idea is to follow the recommended activities by seeing them as guidelines that can be adapted freely and modified when necessary. By using the building blocks and the associated activities to develop the initial workplan for comprehensive cancer control planning, the planning coordinator and evaluation staff or work group members have the basis for a process evaluation. The work plan activities can be modified to reflect the reality of each state or other organization's planning environment once the process is underway and planners understand the process more fully (See Tool #22—Planning Process Monitoring Sheet). Activities for collecting process data can also be designed to support a variety of planning phase activities. Process evaluation can be used to support ongoing monitoring of various aspects of the initiative. Table 8.5 suggests a number of data collection strategies for process evaluation that can be used to monitor and document ongoing activities within the planning phase of the initiative. Note that each evaluation strategy is also a potential source for obtaining process data.

Section 8—References

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Part III: Operationalizing Comprehensive Cancer Control Planning

In Part III, we summarize the guidance document and discuss implementation of the comprehensive cancer control plan. Section 9 presents a suggested timeline using the building blocks throughout the planning process. Section 10 previews what occurs once a plan is completed and disseminated to partners and stakeholders throughout a state or other jurisdiction.

Section 9—Operationalizing Comprehensive Cancer Control Planning

Section 9 provides an overview of the steps involved in developing and completing the comprehensive cancer control plan. The purpose of Section 9 is to assist the reader in translating the Building Blocks of Comprehensive Cancer Control Planning into a timeline. It ties together Part 1, Section 2 (Creating a Vision and Strategies) with Part II (The Building Blocks of Comprehensive Cancer Control Planning) by viewing comprehensive cancer control planning as a sequential process. This timeline should help determine where each of the building block activities is likely to occur during plan development. In the beginning of the planning process, the groundwork for planning is laid. Next, the components of the plan are developed. And lastly, the plan is formalized and published, calling partners and stakeholders and others to action on cancer prevention and control. Experience has shown that the initiation and duration of individual activities may vary markedly, but the stages and steps occur in a fairly regular order.

Table 9.1 provides a chronological reference to the various activities that have been discussed within this document and can be used to assess progress against predetermined, yet flexible, benchmarks. The timeline assumes a 24-month planning period; this time period can vary considerably depending on the context in which planning is occurring. In fact, consider assessing whether adjustments should be made on a regular schedule, such as every three months. Adjustments may include modification of activities as well as of the timeline in accordance with each state or organization's planning goals and approach. Some states or organizations may have a strong cancer control infrastructure and can launch into development of a comprehensive cancer control plan in less than two years. Others may need to spend considerable time developing an infrastructure that can support comprehensive cancer control planning before convening their first partnership meeting. The timeline, then, merely provides a general idea of the order in which activities are undertaken and the proportion of time that is likely to be devoted to certain steps in planning. Note that some activities are ongoing. Details and descriptions of each of the activities listed are included within the section for that building block.

In Table 9.1, several tools are referenced in parentheses. These tools are identified in the key that follows the table. The tools are found in the accompanying *Guidance for Comprehensive Cancer Control Planning,* Volume 2—Toolkit and provide a valuable resource as you continue through the planning process. Many states have provided the tools they used in developing their plans. By using and modifying these tools, you are benefiting from the experience of your peers and using a vast storehouse of knowledge.

Table 9.1 The Stages and Steps of Comprehensive Cancer Control (CCC) Planning†

Approximate Time Line	Enhance Infrastructure	Mobilize Support	Use Data and Research	Build Partnerships	Assess/Address Cancer Burden	Conduct Evaluation
1–3 months	Assess infrastructure needs and capacity* (1).** Gain buy-in from leadership of coordinating agency. Identify or hire a dedicated coordinator and other staff (1). Create a core planning team (1).	Assess current level of support.* Secure funds and in-kind resources for planning (1).	Build linkages to registry and other data agencies and sources.			
4–6 months	Involve other cancer-related staff of the coordinating agency. Develop work plan to guide the planning process (2,22.		Identify available data/ research (7).	Identify potential partners (1,11,14).		Identify resources and staff for evaluation (1). Define planning evaluation questions.
7–9 months	Coordinate and monitor the CCC planning process (ongoing) (2,22,3).	Build support among the public and private sectors (ongoing).		Contact and invite potential partners (9,10). Assess partner interest and capacity* (11,12,13,14). Prepare for 1st partnership meeting (9,10,15).		Document the planning process (ongoing) (3,22).

Approximate Time Line	Enhance Infrastructure	Mobilize Support	Use Data and Research	Build Partnerships	Assess/Address Cancer Burden	Conduct Evaluation
10–12 months			Review data and research as the basis for plan objectives and strategies. Assess data gaps* (7).	Agree on goals, vision and decision-making process with partners. Establish partnership leadership (15). Create work groups (15). Assess partner satisfaction* (ongoing) (20).	Organize partnership around areas of interest.	Identify emerging challenges, solutions, and outcomes of the planning process (ongoing) (19,20).
13–15 months			Collect new data if feasible and/or incorporate data collection/research activities into plan (6,8).	Develop ways for new members to join and nonmembers to provide input.	Determine critical areas of burden and high-risk populations* (16,19). Assess gaps in strategies already in place* (6,7).	Provide TA training on evaluation to partners.
16–18 months		Publicize efforts of the partnership.	Identify or collect baseline data against which to measure outcomes.*		Create measurable goals and objectives for plan* (17).	
19–21 months		Develop approaches for funding plan strategies (4,5). Reassess partnership representation and coverage for implementation.*			Identify possible intervention strategies. Prioritize goals, objectives, and strategies (18).	Create an evaluation plan for implementation.***
22–24 months					Identify implementing organizations for planning strategies (18).	

†Note: The key for numbers enclosed in parentheses is found on page 101.

* Also an evaluation activity.

** The numbers in parentheses refer to planning tools that can be found in the *Guidance for Comprehensive Cancer Control Planning,* Volume 2—Toolkit. See the key below for a list of the referenced tools.

***See References in Sections 8 and 10.

Key to Reference Numbers in Table 9.1

(#)	Tool	Toolkit Section
1	Self-Assessing Capacity for Comprehensive Cancer Control Planning in a State	Enhance Infrastructure
2	Timeline for Planning Tasks	Enhance Infrastructure
3	Chronology of Planning Activities	Enhance Infrastructure
4	Action Group Project Reports	Mobilize Support
5	Project Proposals for Potential Funding	Mobilize Support
6	Cancer Resource Inventory Form	Utilize Data/Research
7	Data Resource Inventory Sheet	Utilize Data/Research
8	Local Health Department Needs Survey Questionnaire	Utilize Data/Research
9	Planning Meeting Invitation Letter	Build Partnership
10	Planning Meeting Registration Form	Build Partnership
11	Planning Partner Interest Forms	Build Partnership
12	Planning Partner Commitment Forms	Build Partnership
13	Work group recruitment/sign-up form	Build Partnership
14	Planning Partner Survey Questionnaires	Build Partnership
15	Proposed Structure and Process for Creating a Comprehensive Cancer Control Plan	Build Partnership
16	Developing Issue Statements for Comprehensive Cancer Control Planning	Assess/Address Cancer Burden
17	Objectives Litmus Test	Assess/Address Cancer Burden
18	Ballot for Goals and Objectives Selection	Assess/Address Cancer Burden
19	Data Maps for Communicating Information to Stakeholders and Communities	Assess/Address Cancer Burden
20	Planning Meeting Assessment Guide	Conduct Evaluation
21	Member Satisfaction Questionnaire	Conduct Evaluation
22	Planning Process Monitoring Sheet	Conduct Evaluation

9.1 Conclusion

9.1.1 Complete the Comprehensive Cancer Control Plan

An important concept to remember is that comprehensive cancer control planning is not a linear process. While writing sections of the plan, those involved in this process will need to revisit the work that led up to the selection of objectives and strategies. And, of course, reports from work groups detailing their priorities and their rationale for selecting them will be refined and incorporated into the plan.

Taking It Off the Shelf

States have used a range of strategies to ensure that the Comprehensive Cancer Control plan is used. Having the plan developed by a broad group of stakeholders using a participatory process is often the first step toward creating a usable plan. The process of meeting to create the plan also helps cement the relationships needed for its implementation.

States have also used a range of dissemination strategies to garner broad support. For example, Kentucky rolled out its draft plan at a statewide cancer conference, and Illinois sent its Action Plan to all legislators in the state and has presented at numerous state, regional, and national conferences.

9.1.2 Write the Comprehensive Cancer Control Plan

Writing the plan largely depends on organizing the goals, objectives, and strategies that have already been developed—along with evaluation measures, timelines, and the names of agencies or organizations responsible for carrying out the strategies—into a coherent and readable document. Work has already been parceled out among work groups, and new external partners may be identified as reviewers.

Generally, the planning coordinator is responsible for overseeing the creation of the comprehensive cancer control plan, but the manner in which work is assigned varies considerably depending on resources, the complexity of the document, and other factors. Although volunteers will probably not be able to take responsibility for writing major sections of

the plan, members will likely want to provide input into the process. Members may, for example, write very discrete sections on areas of their special expertise, or provide internal review and comment. Additionally, core team members, particularly those involved with work groups, may want to take responsibility for sections of the plan. Finally, if resources permit, the coordinating agency may consider hiring a consultant such as a technical writer to translate the ideas of the partnership into a written document.

Whether the plan is written entirely by staff, by staff and a contractor, or by staff with considerable volunteer input, faithfully incorporating the work that has been accomplished to-date is critical. Use the goals, objectives, and strategies that have already been developed to create a coherent document. Be sure to give staff, contractor, or volunteer writers reasonable but strict deadlines so that enough time is available to edit each section for consistency across the individual sections of the plan. Pull the sections together with an introduction, conclusion, and "bridge" sections.

9.1.3 Review the Comprehensive Cancer Control Plan

The elaborateness of the review process needs to be balanced with time and resources available for such review. The emergence of Web sites has made it easier than ever to provide opportunities for public review and comment. A copy of the draft plan can be posted on a Web site from which reviewers can download or print it. This venue can also be used for disseminating the final comprehensive cancer control plan.

If identifying multiple reviewers is desirable, then this is a good time to move further into the network of external stakeholders and obtain input from those who have not been involved throughout the planning process. We recommend obtaining a variety of views without allowing the review process to become unwieldy. Setting strict deadlines for reviewers will help keep the process in motion. Once the review has been completed, the partnership or planning coordinator will need to assess the appropriateness of feedback and make agreed-upon revisions.

Tip. To balance the need for efficiency with the need for buy-in, be sure to identify (1) who will write the plan, (2) when sections of the plan need to be completed, and (3) who will review drafts of the plan.

9.1.4 Produce and Disseminate the Plan

Adaptations to the format are finalized, printing requirements are determined, and a dissemination plan is created. The Comprehensive Cancer Control plan should be disseminated widely. Sufficient copies need to be produced for all partnership members. Other interested parties in the state may include the legislature, the Governor's office, various state health agency divisions and other state agencies, voluntary organizations, and medical and service organizations suggested by partners.

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Section 10—Looking Ahead

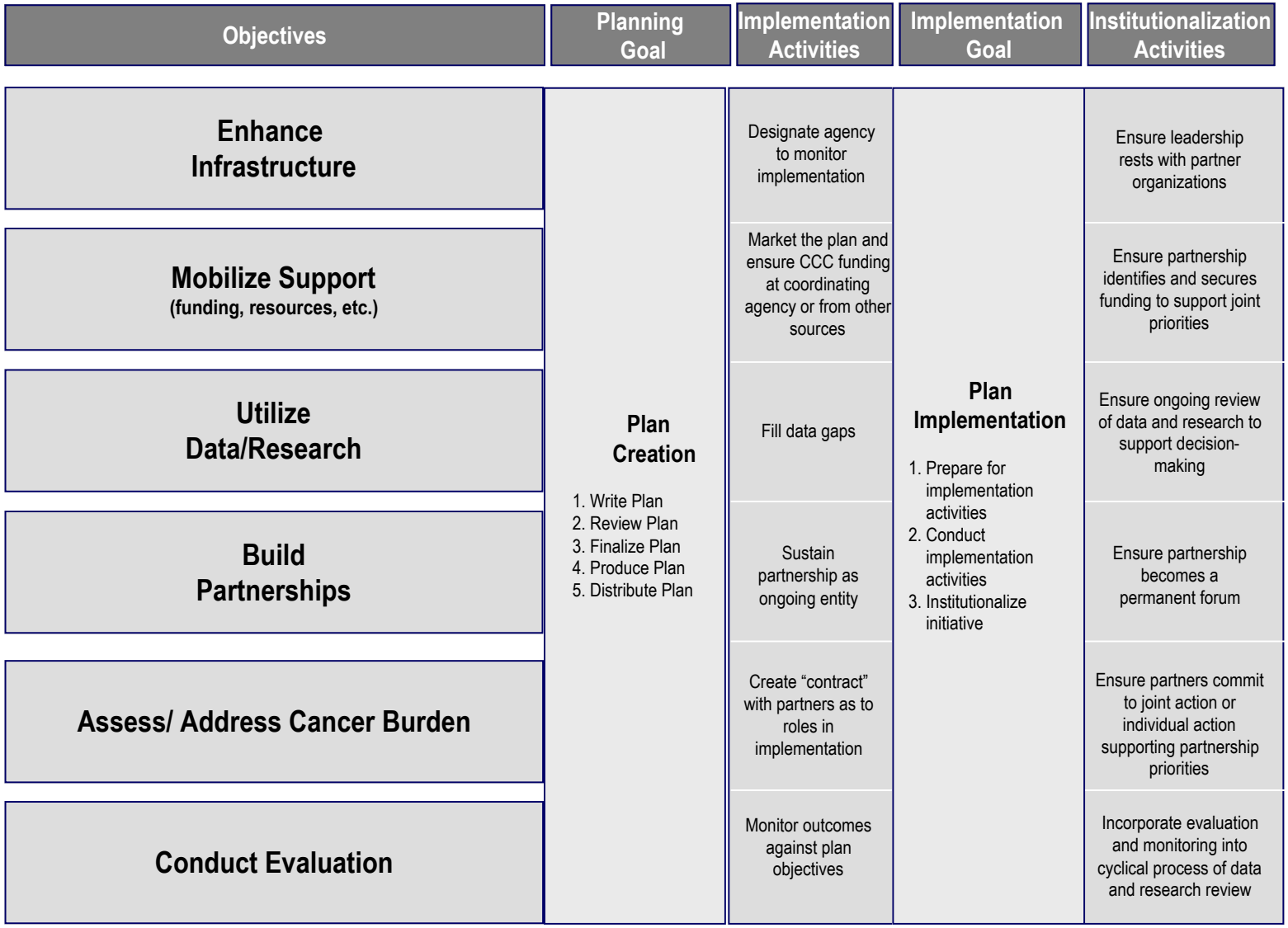
The goal of comprehensive cancer control *planning* is to develop a plan that will guide the implementation of comprehensive cancer control strategies for some period of time, probably between three and five years. Yet, completion of the comprehensive cancer control plan does not mean that the initiative no longer has a reason to exist. Rather, the coordinating agency, the partnership, and other stakeholders are beginning a new phase of their work that involves implementing strategies, mobilizing further support, evaluating progress, and preparing for the next cycle of planning. Once the comprehensive approach becomes the new way of doing business in a state, territory, or tribal organization, then the initiative has become institutionalized.

In fact, completion of the comprehensive cancer control plan marks the first realization of the vision set forth through the exercises in Section 2. At this point, the planners should take another look at that vision, answer the questions in Table 2.1 again, and see if indeed the partnership is where it expected to be and where the partnership intends to go next. In this section, we provide a basic outline of the implementation of the comprehensive cancer control plan, and the institutionalization of the initiative. We also revisit evaluation to consider evaluation of the implementation process and its outcomes and to assess evidence that institutionalization is indeed occurring.

Figure 10.1 extends the Building Blocks for Cancer Control Planning through the implementation of the plan and institutionalization of the initiative. Unlike Part II, where detailed information for each building block activity was provided (based upon years of experience with states that had engaged in comprehensive cancer control planning), the evidence for the implementation and institutionalization activities is less developed at this time. Evidence includes feedback from implementation grantees and model planning states that was presented at conferences, from information shared by other stakeholders, and from the knowledge of other kinds of collaborative efforts. The strongest evidence comes from the case studies completed before embarking upon the model planning project. These case studies were mentioned in Section 1 and included in-depth study of two states that were either implementing a comprehensive cancer control plan (North Carolina) or that were well along in preparing to

implement a plan (Michigan). These two states became implementation grantees in 1998 and were generous in continuing to share their experience with model planning states and with CDC.

Figure 10.1 Building Blocks for Implementing the Plan and Institutionalizing the Initiative.



10.1 Activities for Implementing the Comprehensive Cancer Control Plan

The model in Figure 10.1 shows only one broad activity for each building block objective in each of the columns for implementation and institutionalization. Once planners have reached the point of implementing the plan, they will be in a strong position to determine for themselves what additional activities need to be added to see that the plan is fully implemented and evaluated and that the process becomes institutionalized over time. This will be particularly true if planning has been evidence-based and data-driven, and the partners have invested in the comprehensive plan, provided leadership, and made decisions throughout the process.

The activities suggested in Figure 10-1, along with other activities devised by readers of this Guidance Document as they prepare to implement their own plans, can become the foundation of a revised work plan similar to that developed to guide comprehensive cancer control planning. The revised work plan should include target dates and agencies or individuals responsible for activities.

Designate an agency to coordinate and monitor plan implementation. For most of the model planning states and implementation grantees, this agency has continued to be the same one that led the planning effort. However, this is not necessary for a successful initiative and other options may be considered if it makes sense in a particular state or organization. These options could include transferring implementation to a different agency, placing implementation under the aegis of the partnership, or having a small group of key partners coordinate and monitor plan implementation.

Market the plan and ensure comprehensive cancer control funding at coordinating agency or from other sources. This ongoing activity may require the attention of a special work group, subcommittee, or designated staff. Nongovernment sources of funding (business leaders, specialized foundations) should always be explored, as well as government funds. However, mobilizing support involves more than securing funding for specific strategies; it also requires publicizing the partnership's

Remember—Small victories pay off. Some states that now enjoy fairly robust funding began with very modest resources. Their financial success was achieved through visibility in government, the medical community, and other community sectors, as well as good solid work when developing their CCC plans.

efforts and developing a strong "political will" to support its goals and objectives. Opportunities to present the plan and to point out what it means to the public enhance the probability that community leaders will be aware of comprehensive cancer control and become advocates for implementing portions of the plan. Enhancing support for comprehensive cancer control is even more likely to occur if presenters let audiences know that their participation is needed and valued.

Fill data gaps. This activity speaks to the point made throughout this document that the data needed to develop the best possible objectives and strategies to meet demonstrated needs will not necessarily be readily available when the first cycle of planning is initiated. Or some information on the best approach for implementation of the plan may not be available. If data needs were prioritized as part of the planning process, then these data can be collected as the plan is implemented. As time goes on, new questions arise that may require additional data collection. In fact, the need to obtain new data to keep the process on target and to have the information to evaluate the approach will always exist. As the comprehensive cancer control program matures and is institutionalized, a strategy for identifying data needs and obtaining information can become an ongoing part of planning and implementation.

Sustain the partnership as an ongoing entity. The partnership is at least as critical to implementation as it is to planning. Plan strategies need state and community organizations to carry them out. Evaluation results can help energize the partners, or when results fall short, the partners can help find ways to meet objectives. Changes may need to be made in the partnership structure to reflect its new role—and to reach influential stakeholders with access to funds and other resources. Similarly, changes may need to be made to include community members and leaders of small organizations that are sensitive to the populations that strategies aim to reach.

Create a "contract" with partners as to roles in implementation. Although the "contract" need not be formal, it is the heart of implementation. It signals the commitment of partners to help implement particular goals, objectives, and strategies; to engage in particular roles such as fundraising; to assist in monitoring the plan implementation; or to conduct any of the many tasks necessary to ensure that the plan does not simply sit on a shelf. Formal and public commitment is one way that the partnership takes ownership of the plan and all that it signifies.

Monitor progress and measure outcomes against plan objectives. This activity may require the services of a professional evaluator, depending upon the skills available to the

partnership and is well worth the effort. Without information as to whether outcomes are being met, planning will have been a blind effort. Also, process data will allow for midcourse corrections. This subject is treated more fully below.

10.2 Activities for Institutionalizing Comprehensive Cancer Control

Institutionalization of the initiative will be a very individual process that depends a great deal on the environment in which the plan is being implemented. Some jurisdictions may not wish to institutionalize comprehensive cancer control as an ongoing initiative, and others may incorporate the cancer initiative into other processes, such as a comprehensive chronic disease control initiative. Still, the best way to ensure that the plan is implemented, that evaluation data are used, and that new knowledge is gained from the efforts is to develop a mechanism for comprehensive cancer control in which all cancer-related activities are conducted. Only recently has information become available on how to make this happen. Below are key ideas on institutionalization obtained from work with CDC's comprehensive cancer control initiative to date.

Ensure leadership rests with partner organizations. Through increasing the leadership roles and responsibilities of partners, the partnership body can become a stronger organization in its own right with an enhanced sense of self-identity. This strengthening does not mean that there is no longer a coordinating agency—although it might in those instances where the partnership becomes the coordinating and monitoring body. In most cases, this activity is meant to ensure that there is ownership of the initiative by those organizations that have nurtured the process and are beginning to see rewards from it. This step could involve recruiting chairpersons and work group leaders from among the partners in settings where the coordinating agency held those roles, or creating or enhancing an executive or steering committee that

Remember—Ensuring a high degree of leadership by partners can initially generate additional work for the coordinating agency. Partners need regular progress reports and evaluation data to make decisions. For example, they may also benefit from training in certain skills or tasks that are unfamiliar to them. However, as capacity is increased, additional benefits may accrue to the comprehensive cancer control program as a whole. Also, once the plan is visible and the process enjoys a commitment from legislative and executive branches of government, such as in North Carolina, it may be possible to increase staffing to support the new demands placed on the CCC program.

includes members from partner organizations.

Ensure that the partnership identifies and secures funding to support joint priorities. This activity is a logical outgrowth of the one that precedes it. With ownership increasingly in the hands of partner organizations and their leaders, commitment to finding or generating the resources becomes shared rather than the sole responsibility of the coordinating agency with partners simply acting as advisers.

Ensure ongoing review of data and research to support decision making. This activity may be a staff function or the function of an established work group or committee. It is critical to keeping the process of comprehensive cancer control evidence-based. Ongoing review of data and research can help to make the next cycle of planning (when the current plan expires) more efficient because necessary information is already at hand.

Ensure that the partnership becomes a permanent forum. Although not all states and organizations will choose this route, empowering the comprehensive cancer control partnership to function as a distinct entity with its own rights and responsibilities, perhaps as a consortium of partner agencies, is the clearest strategy for ensuring that the initiative is institutionalized. In Texas, this route was assured from the outset when the legislature formed the Texas Cancer Council as an entity distinct from the state health department. Other states or organizations are likely to take an approach that preserves oversight from a coordinating agency but that empowers the partnership and creates an ongoing structure.

> To pave the way for institutionalizing the comprehensive approach, Maine began early to build capacity and instill a sense of ownership within its partnership, the Maine Consortium for Comprehensive Cancer Control. Partners served as Consortium Co-chairs, as work group facilitators, and as members of the Coordinating Committee. Many key decisions were reached through open discussion of options in the Consortium as a whole. As plan development reached completion, the Coordinating Committee added members and took on the role of guiding the implementation of the plan.

Ensure that partners commit to joint action or individual action supporting partnership priorities. For some states and organizations, this activity already occurred when strategies were first developed and partners assumed responsibility for implementing one or more of them. Other planning bodies took the route of developing plans and then looking for sponsoring organizations

and agencies for implementing strategies. No matter which approach is taken, the partners need to be held accountable. This is one responsibility of the staff or of a work group charged with monitoring plan implementation. The responsibility consists of ensuring that the partners actually carry out their commitments and that the implemented strategies produce their desired results.

Incorporate evaluation and monitoring into a cyclical process of data and research review. As comprehensive cancer control becomes visible, then expectations will increase that outcomes are being met. Evaluation data must be available to meet these expectations or to help understand unanticipated effects. Evaluation data can also be used to answer critics if an outcome is not met. For example, an outcome measure may prove to be unrealistic because the impact of different factors that could not be controlled. Good evaluation data can help to explain the impact of these factors or intervening variables (loss of staff because of budget cutbacks that resulted in fewer early detection activities than planned). By using both process and outcome data, the partnership can learn how a strategy can be improved, and if an objective should be changed in some way to better reflect the needs of the target population.

10.3 Evaluating the Plan Implementation and Plan Outcomes

The information in this section is not meant to replace the evaluation strategy incorporated into the comprehensive cancer control plan (discussed in Section 8). It is meant to extend the concept of evaluation beyond the planning process and even beyond the evaluation of specific plan objectives and strategies. This section discusses evaluation as it pertains specifically to the implementation and institutionalization of comprehensive cancer control. This broad approach to evaluation helps to ensure that the entire comprehensive cancer control process remains evidence based and that information can be obtained readily and communicated to the public, particularly to potential supporters—or to convince those who are skeptical of the benefits of a comprehensive approach to cancer planning and programming.

10.3.1 Process evaluation

In Section 8, we recommended a process evaluation for implementation of the plan and institutionalization of the initiative that focuses on improvement of programmatic activities.

This form of evaluation requires that evaluators, with at least a representative group of partners, determine both *what* implementation of the plan will accomplish and *how* it will be accomplished. This strategy should already be a part of the evaluation plan that was developed as part of the planning process. It can include both special studies of the implementation of particular strategies, particularly those that lend themselves to mixed-method evaluation approaches, as well as monitoring the progress towards completion of strategies. Mixed method studies—for example, combinations of surveys and in-depth interviews or focus groups—may be especially useful where the partnership is taking an innovative approach to a problem. Results of the process evaluation are critical to staying on target and making midcourse corrections.

Another aspect of the process evaluation is to monitor progress towards completion of implementation and institutionalization activities in Figure 10.1, or those that the partnership and coordinating agency flesh out as they prepare to implement the plan. Above, we recommended revising the comprehensive cancer control work plan to include the implementation and institutionalization activities. These activities can be monitored against their target dates, with problems and solutions noted. Of course, changes may be made in the activities as new ones appear to be necessary and ones considered useful turn out to be in need of modification.

10.3.2 Outcome evaluation

Outcome evaluation can be used for marketing the initiative, mobilizing support, and generating accountability data for legislators and other decision makers. Outcome evaluation can also help detect problems in the way the initiative is progressing. Like formative and process evaluation, evaluation of the outcomes of the initiative can also use the model laid out in the Building Blocks for Comprehensive Cancer Control Planning. Planners can specify outcomes anticipated at various points in the comprehensive cancer control process and then devise means to assess or measure whether these outcomes are occurring as expected.

Table 10.1 summarizes for each building block the relationships between identified problems, objectives, and outcomes. Each planning group or organization can define indicators to help determine whether the outcomes for their objectives are being met as their comprehensive cancer control initiative moves forward. As shown in Table 10.1, the outcomes expected during the planning phase are different from those expected during implementation and, as the initiative

moves toward institutionalization, yet another set of outcomes is expected in each of the building block areas. The last three columns list expected outcomes for the implementation and institutionalization phases, as well as the longer term health outcomes that represent a key motivation for undertaking comprehensive cancer planning. These three right-hand columns can be used to structure an outcome evaluation for the implementation and institutionalization phases. For further guidance on evaluating interventions, please refer to "The Guide to Community Preventive Services" at www.thecommunityguide.org.

Table 10.1 Relationship Between Identified Problems, Planning Objectives and Planning/Implementation/Program Outcomes

Identified Problem	Planning Objective	Planning Outcomes	Implementation Outcomes	Program Outcomes	Health Outcomes
Inadequate infrastructure for cancer prevention and control in most states, tribes, and territories.	*Enhance Infrastructure.* Develop and or enhance the management/ administration necessary to support comprehensive cancer prevention and control.	Management and administrative structures and procedures are developed. Planning products are produced, disseminated, and archived.	Sound yet flexible structures are in place, including ongoing monitoring. Partnership members assume increasing responsibility.	Partnership is a new entity and greater than the sum of its parts.	Cancer incidence decreases.
Limited resources for cancer control.	*Mobilize support.* Improve the use of existing resources for cancer programming and increase the level of support available.	Partnership develops priorities for allocation of existing resources. Gaps in resources and level of support are identified.	Existing resources are well used. Resources for cancer control increase, as does coordination of their use.	Ongoing support for cancer control is secured (funding from general revenues).	Cancer morbidity decreases.
Limited data use in decision making.	*Use data and research.* Increase extent to which cancer planning and programming decisions are made on the basis of sound evidence (including feedback from routine evaluation of existing and future programs and services).	Both planning data and research data are reviewed as a basis for needs assessment and strategy development. Data and research gaps are identified.	Data and research are used to support priority setting. Gaps in data and research are addressed.	Cyclical process is in place to assess, strategize, prioritize, implement, and evaluate.	Cancer mortality decreases.
Lack of coordination among cancer control efforts.	*Build partnerships.* Increase awareness and involvement of broad sectors of the citizenry in cancer programming and improve coordination and collaboration among stakeholders.	Original members remain committed as new members join. Partnership and subcommittee meetings are held and attended regularly.	Members commit to and are accountable for implementation. Coordination among programs and services improves and atmosphere grows more collaborative.	Partners advocate and act in a concerted manner and adopt a comprehensive approach.	Disparities among subpopulations are reduced.
Heavy and unequal cancer burden.	*Assess and address cancer burden.* Reduce morbidity and mortality from cancer overall and reduce disparities in cancer burden among subpopulations.	Target areas for cancer prevention and control are selected and prioritized.	Priority strategies are designed and implemented.	Knowledge, attitudes, and behaviors improve. System improves.	

Identified Problem	Planning Objective	Planning Outcomes	Implementation Outcomes	Program Outcomes	Health Outcomes
nsufficient nformation about ffective programs nd services.	*Conduct evaluation.* Develop a strategy for assessing both process and outcomes associated with CCC planning and implementation.	A strategy for assessing the planning process, monitoring implementation, and measuring outcomes is in place.	Implemented strategies are evaluated as is the implementation process. Evaluation data are used appropriately for accountability and program improvement purposes.	Evaluation data are routinely and appropriately incorporated into a cyclical decision-making process (mentioned under Use Data/Research)..	

Monitoring actual outcomes against anticipated outcomes in each of the building block areas over time will help planning coordinators and their core teams determine whether their own processes are evolving as expected or are turning into something quite different. Critical questions to ask include

Are implementation and institutionalization outcomes occurring as expected?

Are indicators of change that can lead to long-term health outcomes being achieved?

Evaluators and partners can work together to develop solutions if the answers to these questions are not as positive as hoped.

This section has been a very brief treatment of a topic critical to the ongoing success and effectiveness of the comprehensive cancer control initiative. Again, review some of the resources listed in this document and consider the use of evaluation assistance from universities or local firms. By taking an improvement-centered approach to evaluation, the comprehensive cancer control staff and their partners can do much to lay out the vision, goals, and objectives for evaluation. They can also more effectively monitor the progress of the initiative, understand the problems that may be present, and devise solutions to those problems.

Remember—Some variation from expected outcomes is acceptable if there are valid and compelling reasons for it, but numerous or extreme variations may indicate that the process has gotten off track or is heading into uncharted territory. Reassessment by the coordinating agency and partnership leadership may be warranted.

Section 11—Conclusion

The overarching purpose of comprehensive cancer control is to make a difference in the lives of people by decreasing the burden of cancer on individuals, families, and communities. Although it may take time to see these changes, the eventual outcomes that the initiative seeks to achieve are to

Decrease morbidity and mortality from cancer.

Reduce disparities in incidence, morbidity, mortality, and access to services.

This document has provided guidance on how to develop a new approach to cancer prevention and control to reach these outcomes. The route is not always straightforward, but, as demonstrated throughout, it is one that can have numerous benefits to both those engaged in the process and the constituencies that they serve.

At this time, comprehensive cancer control is still a fairly new initiative, coming to the fore only in the mid-1990s. Yet, at the turn of the 21st century interest in this approach burgeoned. This guidance document is meant to assist the pioneers who are developing comprehensive cancer control programs. Very likely, in the next several years, they will have much new knowledge to add to the field. Therefore, comprehensive cancer control continues to be an evolving process that will yield new lessons well into the future. For this reason, this document is presented as a "living document"—one that will be expanded and modified as the knowledge evolves.

Glossary

Glossary

Term	Definition	Section Introduced
Activity	The comprehensive cancer control process consists of six building blocks. Each building block is composed of a series of activities. Each activity was derived from an assessment of the way in which six model planning states actually developed a comprehensive cancer control process. Users of this document may wish to modify activities to meet their own planning environments.	1
Assess/Address Cancer Burden	A building block of comprehensive cancer control planning. Its objective is to reduce morbidity and mortality from cancer overall and reduce disparities in cancer burden among subpopulations.	1
Build Partnerships	A building block of comprehensive cancer control planning. Its objective is to increase involvement of broad sectors of the citizenry in cancer programming and improve coordination and collaboration among stakeholders.	1
Capacity Assessment	An activity that yields an understanding of both strengths and needs as they relate to comprehensive cancer control. The prior experience and current resources within the coordinating agency, as well as outside it, which could positively contribute to meeting the challenges of comprehensive cancer planning are systematically reviewed. In this way, the agency can develop a full picture of the situation for planning in the state.	3
Cancer Stakeholders	Those individuals or groups who are particularly concerned with issues and programs that relate to cancer prevention, control, treatment, or survivorship as they relate to the individual and community. Stakeholders may be representatives of cancer organizations (e.g., American Cancer Society) or they may come from organizations with a broader mandate. For example, representatives of rural health programs or minority advocacy groups may be cancer stakeholders since their concerns (e.g., access to care or cultural competency) are part of the comprehensive cancer control agenda.	1
Case Study	A time-bound study of a program, project, intervention, or social unit within its normal daily context.	1
Collaboration	A group of diverse individuals who work together to achieve a common goal.	1
Component	A section or subsection of the comprehensive plan that deals with a specific area of cancer prevention or control (risk factor, cancer site).	1

Comprehensive Cancer Control	An integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation.	1
Core Team	Those health agency staff involved in the comprehensive cancer planning process as a regular part of their responsibilities.	2
Early Detection	The detection of disease among people who do not yet have symptoms, usually through a screening test.	1
Enhance Infrastructure	A building block of comprehensive cancer control planning. Its objective is to develop and enhance the management and administration necessary to support comprehensive cancer prevention and control.	1
Executive Committee	A select group of members drawn from a larger body to help guide the deliberations and enhance the efficiency of the larger group. Some partnerships may prefer a coordinating committee or steering committee instead of, or in addition to, an executive committee.	3
Expanded Team	Health agency staff who support the comprehensive cancer planning process in various ways that are limited in time and scope.	3
Facilitators	Those elements identified during an initial capacity assessment that are most likely to promote the success of comprehensive cancer planning.	3
Formative Evaluation	Evaluation that furnishes information that will guide program improvement. Its purpose is to help form or shape the program to perform better. It may relate to the need for the program, the program concept and design, its implementation, its impact, efficiency, and effectiveness.	2
Framework	A general model or outline for the complex cancer planning process. It consists of four phases (see below) that are broadly defined to allow for differences from one planning environment to another.	1
Goal	A general statement of what will be accomplished in the long-term (the 3 to 5 years covered by the plan).	2
Guidelines/Guidance	Suggestions and recommendations for engaging in a comprehensive cancer planning process. As with the framework, actual use of the guidelines is expected to vary considerably.	1
Health Outcomes	These are the distal or ultimate outcomes of the comprehensive cancer control process—decreased cancer morbidity and mortality overall and reduced disparities in morbidity and mortality among different populations. This is what is expected to occur as a result of meeting the goals and objectives of planning, implementation, and institutionalization.	1

Implementation	The process of carrying out planned strategies to meet specified goals and objectives.	1
Inclusiveness	Involvement in the planning process by a broad and diverse array of stakeholders.	6
Institutionalization	The process by which comprehensive cancer control becomes the usual way of conducting cancer-related activities in a state, territory, tribe, or other jurisdiction or agency or organization.	1
Intervention	A means to forestall an undesirable outcome or promote a desired outcome.	1
Jurisdiction	States, tribal organizations, territories, counties, cities, regions (several contiguous states), or other geographic or political unit.	1
Laying the Groundwork	The steps and activities that help to initiate comprehensive cancer control and keep it on track. These activities begin early, as soon as comprehensive cancer control is considered, and need to be maintained throughout the process.	1
Member	For the most part, this term is used interchangeably with partners. However, a subtle distinction is that members of either the partnership, work group, core, or expanded team are actively involved in attending meetings and carrying out activities. A partner may have a more limited role, such as participating only in review of documents. This distinction is made to include experts and stakeholders who can make important contributions but are not available for regular meetings.	2
Milestone	A benchmark that indicates that an outcome is being attained.	2
Model Planning States	The six model planning states are Arkansas, Illinois, Kansas, Kentucky, Maine, and Utah. The "model planning states" were selected according to a set of criteria that considered demographics, geographical spread, type of organizational structure (more centralized or diffuse), and willingness to participate.	1
Mobilize Support	A building block of comprehensive cancer control planning. The objective is to improve the use of existing resources for cancer programming and increase the level of support available overall.	1
Objective	A means to achieve a goal accomplished through implementation of one or more strategies during a specified time frame. This accomplishment should be measurable.	1
Outcome Evaluation	Evaluation of the observable effects of a program, in this case, planning, implementation, and institutionalization outcomes**.**	2

Palliation	Alleviation of pain or other symptoms without curing the underlying disease process.	1
Partner	An individual or organization that supports or participates in comprehensive cancer planning or implementation. Partners may commit organizational resources to planning or implementing strategies for comprehensive cancer prevention or control.	
Partnership	The coalition, committee, consortium, or task force that spearheads the comprehensive cancer approach, as well as other supporters of the process.	1
Phase	The initial framework for comprehensive cancer control was divided into four phases: (1) setting optimal objectives, (2) determining possible strategies, (3) planning feasible strategies, and (4) implementing effective strategies.	1
Prevention	*Primary prevention* refers to the complete prevention of disease, often through methods that inhibit exposure to risk factors (e.g., preventing exposure to tobacco smoke). *Secondary prevention* is meant to inhibit or reverse the effects of disease in its early stages, mainly through early detection (using the Pap test to discover and treat cervical neoplasia). *Tertiary prevention* identifies the disease process and attempts to prevent further disability and restore a higher level of functioning (pain management or use of prostheses where indicated). In this document, primary prevention is synonymous with prevention. Secondary prevention is covered by early detection and treatment. Tertiary prevention is also addressed through treatment, as well as by rehabilitation and palliation.	1
Process Evaluation	Evaluation that verifies what the program is and whether or not it delivered as intended to the target recipients.	2
Program Outcomes	Sometimes called proximal or immediate outcomes, program outcomes are directly linked to the activities of planning or to strategies of implementation. They indicate if changes are occurring in the short-term as planned.	1
Rehabilitation	Restoration of the ability to function as normally as possible when function has been compromised by disease, treatment for disease (surgical removal of a diseased part), disability, or injury.	1
Stage	When approached from a time-phased perspective, the comprehensive approach to cancer prevention and control is divided into three stages that are further subdivided into steps and activities (cross-cutting the building blocks of planning). The three major stages are (1) lay the groundwork for planning, (2) develop the comprehensive cancer control plan components, and (3) complete the comprehensive cancer control plan.	9

States, Tribes, and Territories	Major jurisdictional units of the United States. In the late 1990s, comprehensive cancer control was initiated in six model planning states and implemented in several states and one tribal organization. The approach can be transferred to a variety of other settings, as well. Therefore, for conciseness the guidance document uses the term states and other organizations to designate its broad target audience	1
State Health Agency	The agency within a state's government that is primarily responsible for protecting and promoting the health of the public.	1
Step	Each of the three stages of comprehensive cancer control planning has been divided into three or four steps. The stages are reasonably fixed across states and other organizations; steps are less fixed, and the activities are likely to vary in different planning environments.	9
Strategy	A means to accomplish an objective, which in turn is a means of achieving a goal. A strategy may be a health intervention at the individual or population level, but it can also refer to such things as a systems change initiative (education or legislation) or further data collection.	1
Subcommittee	Although the term may be synonymous to work groups formed to undertake specific tasks on behalf of a larger committee, subcommittees may also have unique functions, such as subcommittee of a work group, advisory committee to the partnership, or ad hoc committee for special topics.	3
Treatment	Strategy for curing disease or healing symptoms. In public health and program evaluation, a treatment may also be a condition in which a group of people is exposed to an intervention meant to change knowledge, attitudes, and behavior.	1
Use Data/Research	A building block of comprehensive cancer control planning. Its objective is to increase extent to which cancer planning and programming decisions are made on the basis of sound evidence (including feedback from routine evaluation of existing and future programs and services).	1
Vision Statement	A statement that attempts to capture the ultimate outcome envisioned by the members of the partnership.	2
Work Group	The smaller groups into which the partnership is divided to accomplish the concrete tasks of planning. Work groups are usually divided according to the components of the plan (e.g., prevention, early detection, cancer site, risk factor, or other issue) and are charged with developing goals, objectives and strategies in line with that component.	2
Work Plan	A plan that outlines the individual steps required in order to accomplish a complex undertaking.	2