

Increasing Access to Cancer Care:
*An Action Guide for Comprehensive Cancer
Control Coalitions*

Acknowledgments

C-Change commissioned Strategic Health Concepts [SHC] to develop this Access to Care Guidance Document for use by State, Tribe, Territory and Pacific Island Jurisdictions Comprehensive Cancer Control Coalitions. We gratefully acknowledge the efforts of SHC's Karin Hohman and Leslie Given in developing this guidance document.

In addition, C-Change acknowledges the support and guidance of the Access to Care Guidance Document Project Advisory Committee members in preparing this document.

Pam Bennett, RN, BSN
Executive Director, Healthcare Alliance
Development
Purdue Pharma, L.P.

Patricia Schoonmaker
Project Coordinator
Oregon Partnership for Cancer Control
Oregon Health Services

Dan Cohen
Senior Vice President
Government Relations & Public Policy
US Oncology

Shinobu Watanabe-Galloway, Ph.D.
Program Director
Northern Plains Comprehensive Cancer
Control Program

Leslie Given, MPA
Strategic Health Concepts

Steve Taplin, MD
Senior Scientist
National Cancer Institute

Gary Gurian
Director, C-Change

Armin Weinberg, PhD
Co-Founder, Intercultural Cancer Council
Baylor College of Medicine

Karin Hohman, RN, MBA
Strategic Health Concepts

Maureen J. Williams
Special Assistant to Deputy Administrator
Health Resources and Services
Administration
Office of the Administrator

Holly Howe, PhD
Executive Director
North American Association of Central
Cancer Registries

Philip Huang, MD, MPH
Medical Director
Chronic Disease Prevention
Texas Department of State Health Services

Charlton Wilson, MD FACP
Associate Director
Phoenix Indian Medical Center
Centers of Excellence

Table of Contents

Introduction.....	1
Purpose & Suggested Uses.....	3
Access to Cancer Care Issues.....	4
Actions to Improve Access	6
Addressing Access Issues Through CCC Plans	11
10 Elements of a Successful CCC Coalition Access to Cancer Care Efforts.....	13
Increasing Access to Care: Six Success Stories.....	34

Introduction: Access to Cancer Care and Comprehensive Cancer Control

Access (āk'sēs) *n.* 1. A means of approaching or nearing; passage. 2. The act of approaching. 3. The right to enter or make use of. 4. The state or quality of being easy to approach or enter.¹

Access means different things to different people. In the world of cancer control “access” is defined in many ways, often in terms of one person’s entry into cancer care that is on par with another’s. Access, as defined by the Institute of Medicine (IOM, 1994), is the “timely use of personal health services to achieve the best possible health outcomes.” For certain, access to cancer care is a complex issue. It is more than just “getting in the door” to care; it is about access to care that is timely, appropriate, of high quality, culturally relevant, affordable and coordinated. In addition, access is not limited to cancer treatment services but also includes cancer prevention, screening, and diagnostic services.

Facts about access to health care²:

- One-third of all Americans and two-thirds of low-income Americans are uninsured or underinsured at some point during the year.
[Source: The Commonwealth Fund, Learning from High Performance Health Systems Around the Globe, January 2007]
- In 2006, 47 million people were without health insurance coverage, up from 44.8 million people in 2005.
[Source: DeNavas-Walt C, Proctor BD, Smith, J. Income, Poverty, and Health Insurance Coverage in the United States: 2006. Washington, DC: U.S. Census Bureau; 2007]
- Family health insurance premiums have risen 87 percent since the year 2000, but median family incomes have increased by only 11 percent.
[Source: The Commonwealth Fund, Learning from High Performance Health Systems Around the Globe, January 2007]
- Uninsured, black, Hispanic, and low-income patients are less likely than white, high-income, and insured patients to receive recommended care and are more likely to be admitted to the hospital for potentially preventable conditions.
[Source: The Commonwealth Fund, US Health System Performance: A National Scorecard, September 2006]

¹ American Heritage Dictionary, 1985

² American Cancer Society website <http://www.cancer.org/docroot/subsite/accesstocare/index.asp>

- Hispanics and African Americans also have differential access to a regular doctor or source of care, with Hispanics particularly at risk. As many as 43 percent of Hispanics and 21 percent of African Americans report they have no regular doctor or source of care, compared with 15 percent of whites and 16 percent of Asian Americans. [*Source: The Commonwealth Fund, Closing the Divide: How Medical Homes Promote Equity in Health Care, June 2007*]
- The shortage of health care professionals working in American Indian and Alaska Native communities - fewer than 90 doctors for every 100,000 Native Americans, compared to 229 per 100,000 nationally - makes health care access an even more challenging issue to address among the population. [*Source: American Cancer Society. Cancer facts and figures 1997: racial and ethnic patterns.*]

Currently in the United States there is an approach to cancer prevention and control that could positively and fundamentally affect the issues surrounding access to cancer care. Comprehensive cancer control (CCC) is defined as a collaborative process through which a community and its partners pool resources to reduce the burden of cancer.³ Put simply, CCC is people and organizations working together to achieve outcomes they could not achieve alone. All states and many tribes, territories and United States Pacific Island Jurisdictions have created coalitions and strategic cancer plans aimed at addressing cancer issues, including access to care. And they are implementing these plans using a variety of strategies, including policy change.

This Guide is focused on what CCC coalitions can and are doing to address the complex issues surrounding access to cancer care. For that reason, we define access in terms of the outcomes that are possible through comprehensive cancer control efforts: **Increased access for all people to cancer care that is high quality, timely and appropriate.**

C-Change supported the development and dissemination of the Guide as part of its ongoing commitment to building capacity for comprehensive cancer control among states, tribes, territories and U.S. Pacific Island Jurisdictions. C-Change is committed to work with other national comprehensive cancer control partners to provide opportunities for CCC coalitions to use the ideas and tools in this Guide to increase access to quality cancer care. **Appendix A** contains a brief overview of the CCC National Partnership efforts.

³ Centers for Disease Control and Prevention, National Comprehensive Cancer Control Program website. Available at www.cdc.gov/cancer/ncccp/.

The Guide's Purpose and Suggested Uses

Purpose of the Guide

The purpose of this Guide is to help CCC coalitions determine specific actions to increase access to cancer care.

Users of the Guide

The Guide is intended for CCC coalitions across the United States. It is anticipated the coalition leadership (Coalition Chairs, Executive Committee members, Program Directors, Workgroup Leaders) will be instrumental in encouraging and supporting the use of the Guide, either themselves or providing the guide to appropriate workgroups or individuals in the coalition.

Organization of the Guide

This Guide is organized in five main parts:

- 1) **Access to Cancer Care Issues**
A description of the access to cancer issues that face CCC coalition in their work.
- 2) **Actions to Improve Access**
A summary of key published literature, including bottom line conclusions from each article.
- 3) **Addressing Access Issues Through CCC Plans**
Examples of how CCC coalitions plan to address access issues through their CCC plans.
- 4) **10 Elements of a Successful CCC Coalition Access to Cancer Care Effort**
Ten elements to guide CCC coalitions in their efforts to address access to cancer care issues.
- 5) **Increasing Access to Care: Six Success Stories**
Success stories from CCC coalitions and others about how they have made an impact of access to quality cancer care.

Suggested Uses of this Guide

It is anticipated that the Guide will be used by a small group of people within the CCC Coalition that want to focus on addressing access to cancer care issues. The Guide is designed to be flexible and not prescriptive; therefore the group should feel comfortable in using the Guide to best meet their needs. The group can work through the Guide section by section, answering and documenting discussion highlights and decisions as they progress through each section of the Guide and each of the 10 elements. Adding to the questions to be discussed and skipping forward to other sections are all expected and acceptable when using the Guide. Make it fit your needs.

Access to Cancer Care Issues

Increasing access for all people to cancer care that is high quality, timely and appropriate is a daunting problem. Understanding the complexity and extent of the problems associated with access to cancer care is the first step in identifying solutions.

Through a process of examining the burden of cancer and gaps in policies, programs and services, state CCC coalitions have identified both common and unique access to cancer care issues. Access to cancer care issues included in state cancer plans include:

- No or limited medical insurance coverage
- Limited reimbursement for cutting-edge cancer care
- Lack of adequate and sustained funding for state Medicaid programs, including prescription drugs
- Lack of knowledge and access to clinical trials
- Long distance to a cancer care facility
- No primary care provider
- Limited access to health care providers in rural areas, especially oncologists
- Transportation limitations
- No childcare services for cancer patients
- Language and cultural barriers
- Lack of education for providers in the use of standard treatment guidelines and protocols
- Regulations or policies that restrict or create barriers to provide and receive quality cancer care
- Lack of data regarding the extent of the access problem
- Lack of advocacy for increased access
- Limited financial counseling and support for individuals who need help with paying for their care
- Limited access to information about available services

From Iowa Cancer Plan

Cancer Problem #3:

Patients across Iowa do not have equal access to cancer care. Barriers to quality treatment include lack of access due to location (rurality), finances (insurance status), culture, language, and/or lack of information or awareness.

Issues and Opportunities

The complexity of access to cancer care issues can be examined more easily by framing the issues in the following way:

Issue	Description
Availability	Spectrum of services available in a community, gaps in services, availability of appropriate health professionals, lack of information about available services.
Accessibility	Transportation issues, geographic location of services, lack of source for primary care, limited patient navigation services, hours of care, regulations that hinder access.
Affordability	No insurance, limited coverage, low reimbursement.
Acceptability	Cultural sensitivity, language barriers, options for treatment.
Accountability	Quality of services, lack of coordinated care, etc.

Likewise, framing opportunities can be helpful in identifying the scope of what can be done to address the issues:

Opportunity	Description
Policy	Advocating for legislative or regulatory changes that increase access for all, for example mandated insurance coverage of colorectal cancer screening. Support for organizational policy changes that increase access, for example largest employer in the state expands coverage of clinical trials for employees. Identifying policies or regulations that restrict or create barriers to providing quality cancer care and changing those policies.
Program	Enhancing or developing specific interventions to understand and/or solve problems, for example adding colorectal cancer screening to existing breast and cervical cancer screening.
Practice	Wide scale systems changes that improve delivery of care and increase access to services and may include policy and program solutions, for example within a region of the state hospitals, community health centers and the CCC coalition partner to develop a seamless system of education, screening, referral and patient navigation to increase breast, cervical and colorectal cancer screening.

These frameworks will be used throughout the Guide to better focus on what can and is being done through comprehensive cancer control to address access to cancer care issues.

Actions to Improve Access

A search of the internet using the phrase “access to cancer care” yields more than 20 million hits. A recent search on Pub Med of articles about access to cancer care published in the last 5 years yields nearly 1,000 results. Sifting through all of this information is time consuming and in the end, may not help us understand what to do in our situation, in our community.

There have been a number of peer reviewed published articles and reports that may point us in the right direction. The good news is that there are recurring themes and recommendations running through the evidence. Here are just a few that are relevant to CCC efforts:

Publication	Opportunities to Increase Access to Cancer Care
<p>Ensuring Quality Cancer Care, Institute of Medicine, National Cancer Policy Board, Maria Hewitt and Joseph V. Simone, editors; 1999</p>	<ul style="list-style-type: none"> • Ensure that patients undergoing procedures that are technically difficult to perform and have been associated with higher mortality in lower-volume settings receive care at facilities with extensive experience (i.e., high-volume facilities). • Use systematically developed guidelines based on the best available evidence for prevention, diagnosis, treatment, and palliative care. • Measure and monitor the quality of care using a core set of quality measures. • For each individual with cancer ensure: <ul style="list-style-type: none"> ○ that recommendations about initial cancer management are made by experienced professionals; ○ an agreed-upon care plan that outlines goals of care; ○ access to the full complement of resources necessary to implement the care plan; ○ access to high-quality clinical trials; ○ policies to ensure full disclosure of information about appropriate treatment options; ○ a mechanism to coordinate services; and ○ psychosocial support services and compassionate care. • Ensure quality of care at the end of life, in particular, the management of cancer-related pain and timely referral to palliative and hospice care. • Invest in clinical trials to address questions about cancer care management. • Implement a cancer data system that can provide quality benchmarks for use by systems of care

Publication	Opportunities to Increase Access to Cancer Care
	<p>(such as hospitals, provider groups, and managed care systems).</p> <ul style="list-style-type: none"> • Public and private sponsors of cancer care research should support national studies patterns of cancer care and factors associated with the receipt of good care. Research sponsors should also support training for cancer care providers interested in health services research. • Services for the un- and underinsured should be enhanced to ensure entry to, and equitable treatment within, the cancer care system. • Studies are needed to find out why specific segments of the population (e.g., members of certain racial or ethnic groups, older patients) do not receive appropriate cancer care. These studies should measure provider and individual knowledge, attitudes, and beliefs, as well as other potential barriers to access to care.
<p>Facing Cancer in Indian Country: The Yakama Nation and Pacific Northwest Tribes, President's Cancer Panel Annual Report, US Dept of Health and Human Services, National Cancer Institute; 2002</p>	<ul style="list-style-type: none"> • Increase funding for Indian health care through the Indian Health Service. • US Dept of Health and Human Services should convene relevant agencies to find greater synergies and cost efficiencies among existing cancer programs for Native Americans. • Establish patient navigator programs to help Native American cancer patients and those at risk enter the health care system, get assistance and access care. • Develop more accurate data on the cancer burden experienced by Native Americans. • Look at existing effective models for improving care. • Conduct additional research to better understand relationships between environmental exposures and cancer in Pacific Northwest Native Americans. • Support legislation aimed at continuing funding and increasing access to cancer care for Native Americans.
<p>Fulfilling the Potential of Cancer Prevention and Early Detection, Institute of Medicine, National Cancer Policy Board, Curry, Byers and Hewitt, editors; 2003</p>	<ul style="list-style-type: none"> • Reduce the demand for tobacco by increasing tobacco taxes and reinvest revenues in tobacco control. • Develop and implement a comprehensive cancer

Publication	Opportunities to Increase Access to Cancer Care
	<ul style="list-style-type: none"> control plan in every state. • Assure public and private insurers cover prevention and early detection services as essential benefits. • Increase support for primary care programs for the uninsured. • Increase support for federally funded breast, cervical and colorectal cancer screening programs. • Improve patient access to prevention and early detection services through supportive management systems.
<p>Making Cancer Health Disparities History: Report of the Trans-HHS Cancer Health Disparities Progress Review Group, US Department of Health and Human Services; 2004</p>	<ul style="list-style-type: none"> • Implement evidence-based tobacco control strategies, including those that create financial disincentives. • Ensure those at highest risk have access to appropriate screening and follow up services for breast, cervical and colorectal cancer. • Support culturally, linguistically and literacy specific approaches for eliminating cancer health disparities. • Ensure every cancer patient has access to state of the science care. • Encourage government to collaborate with private and voluntary sectors to ensure that all Americans receive the full range of lifesaving information, services and quality care from cancer prevention to screening to diagnosis to treatment.
<p>A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies, Section VII: Access to Quality Care and Services, US Department of Health and Human Services, Centers for Disease Control and Prevention with the Lance Armstrong Foundation; 2004</p>	<ul style="list-style-type: none"> • Develop, test, maintain and promote patient navigation systems for cancer survivors. • Educate decision-makers about economic and insurance barriers for cancer survivors. • Establish and disseminate guidelines that support quality and timely service provision to cancer survivors. • Assess and enhance provision of palliative services to cancer survivors. • Establish integrated multidisciplinary teams of health care providers.

Publication	Opportunities to Increase Access to Cancer Care
Assessing the Quality of Cancer Care: An Approach to Measurement in Georgia , Institute of Medicine, Committee on Assessing Improvements in Cancer Care in Georgia, Jill Eden and Joseph V. Simone, editors; 2005	<ul style="list-style-type: none"> • Establish measures for the quality of cancer care. • Develop the capacity to assess the experience of cancer patients and to measure disparities in the quality of cancer care.
Cancer Screening: Payer Cost/Benefit thru Employee Benefits Programs , Commissioned by C-Change and the American Cancer Society, Bruce Pyenson and Patricia Zenner, Milliman, Inc.; 2005	<ul style="list-style-type: none"> • Cancer prevention and early detection is low cost. • Costs of treating and caring for people with cancer are high. • Investment in prevention and early detection makes financial sense.
Enhancing Cancer Treatment through Improved Understanding of the Critical Components, Economics and Barriers of Cancer Clinical Trials , C-Change and the Coalition of Cancer Cooperative Groups; 2006	<p>Work with policy makers to:</p> <ul style="list-style-type: none"> • Ensure adequate funding for clinical trials. • Support high quality tissue and serum banking systems required to enable research. • Ensure more efficient and effective regulatory process for investigators so more patients participate in clinical trials. • Promote general public and physician education about clinical trials to ensure adequate participation.

Adapting the Solutions to Meet Your Needs

The recurring themes and recommendations in the table above tell us what should be done to increase access to cancer care, through policy, program and practice approaches. Common recommendations include increased support for primary care, increased funding for un- and underinsured populations, measuring and tracking quality of care, increased support for tobacco control efforts, etc.

Countless other published studies illuminate how to implement specific strategies in specific communities, such as increasing breast cancer screening among African American populations. In the end, the best advice is to make the solution fit the problem and to ensure that evidence is used to inform action. Some additional resources that explain what should be done, how others have done it and how you can adapt the solution to your situation include:

- The Guide to Community Preventive Services: <http://www.thecommunityguide.org/>
- The Guide to Clinical Preventive Services: <http://www.ahrq.gov/clinic/prevenix.htm>
- Research-Tested Intervention Programs: <http://rtips.cancer.gov/rtips/index.do>

- The National Cancer Institute’s *Using What Works: Adapting Evidence-Based Programs to Fit Your Needs*: http://cancercontrol.cancer.gov/use_what_works/start.htm

Many of these resources and others can be accessed through Cancer Control P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-Based Tools) at <http://cancercontrolplanet.cancer.gov/>.

Published evidence specific to the implementation of CCC plan priorities to increase access to cancer care are virtually non-existent. CCC coalitions and programs should seek opportunities to publish their efforts and establish the “evidence base.” The web portal Cancer Control P.L.A.N.E.T. provides an avenue for sharing research tested intervention programs. Likewise, many of the websites and online journals referenced in this Guide offer users the ability to submit peer-reviewed work and/or evaluated successful strategies.



From Oregon Cancer Plan

*“Access to quality treatment can be a reality
when people begin working together.”*

—CELESTE WHITEWOLF
STAGE III BREAST CANCER SURVIVOR,
DIAGNOSED IN AUGUST 1998

Addressing Access Issues Through CCC Plans

Comprehensive cancer control coalitions are making strides in addressing access to cancer care issues. This section highlights how coalitions have address access issues in their CCC plans, including the types of goals and objectives in related to access. The last section of the Guide includes a number of in-depth descriptions of highly successful efforts to increase access to cancer care.

Examples of Access Goals, Objectives and Strategies from CCC Plans

Every current CCC plan identifies access as a major issue to be addressed. There is variation in how CCC coalitions looked at access in their plan: some plans have an access to care chapter, some include the majority of access issues in a quality of care or disparities chapter, some include overcoming access as a major goal of their work and some have objectives scattered through the plan- across the continuum of care- that touch on access issues. All CCC plans are available on Cancer Control P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-Based Tools) at <http://cancercontrolplanet.cancer.gov/>.

Some examples taken directly from CCC plans include:

- **New Jersey: Overall Goal:** To assure that the people of New Jersey have increased access to high-quality cancer prevention, education, detection, and treatment services, including research studies, and to provide sufficient resources to meet these needs.
- **Washington: Objective 14.5:** By 2008, increase the proportion of Washington residents who report having a usual source of primary care to 90%. Baseline: 86% (\pm 1%). Data Source: 2000 BRFSS. **Strategies:** Promote programs that provide incentives for medical professionals to work in primary care. Educate the public regarding the importance of establishing a usual source of primary care. Discourage the use of emergency departments for primary care services.
- **District of Columbia: GOAL:** To improve access to primary and cancer care for DC residents. **Objectives and strategies:**
 - Create a coordinated patient navigation system by 2008.
 - Establish affiliation agreements between the community health centers, hospitals, and health care providers for diagnostic follow-up and treatment by 2007.
 - Improve access to public transportation for cancer patients by 2010.
 - Increase the participation of eligible minority residents in cancer-related clinical trials by 15% by 2010.
 - Educate consumers about access to cancer screening, care, and other services by 2010.

Massachusetts Comprehensive Cancer Control Coalition Plan

Goal: Reduce the mortality rate from colorectal cancer

Strategies:

- Remove structural barriers like health insurance coverage and transportation.
- Work with community health clinics to include a system for ensuring early detection screenings, case management, and patient reminders systems.
- Encourage providers to establish case management and patient reminder systems.

PRIORITY GOAL AND OBJECTIVES

GOAL A Every Pennsylvanian will have access to primary care, cancer prevention/screening, and cancer care by eliminating barriers (geography, transportation, income, information access, language, culture, and psychosocial).

From Pennsylvania Cancer Plan

STRATEGY A: Develop five "Regional Partnership Networks" (RPNs) dedicated to breaking down barriers to access of cancer care.	
Action Plan	Recommended Implementation Steps
Conduct a comprehensive evaluation of current cancer care capacity in the state.	Convene a task force to develop an evaluation plan.
	Evaluate workforce supply, types of treatments available/ treatment resources, housing, transportation, translation services and other areas. For rural areas, evaluate rural patient utilization of out-of-area cancer care, type of care sought and type of provider access.
	Conduct an academic literature search on the impact of lack of access to the quality of care received by patients who are under/uninsured. Detail existing studies on the economic impact to communities where there are disparities/lack of insurance: rural and urban.
	Compile list of charity care donations of local/regional health care providers.
	Collect incidence and mortality rates from the Wisconsin Cancer Reporting System.
	Survey impact of new Medicare guidelines on potentially limiting availability of chemotherapy in rural areas.
	Complete comprehensive report outlining evaluation findings.
Develop and implement a strategic plan for each RPN to overcome barriers to cancer care.	Work with local partners to identify leaders and stakeholders who are interested in developing five RPNs in Wisconsin.
	Convene statewide summit of key stakeholders to evaluate data and develop five RPNs in Wisconsin.
	Periodically convene the five RPNs in order to exchange information, plan, and execute statewide initiatives.

From Wisconsin Cancer Plan

Cancer plans are blueprints for action. They lay out a plan for what to do, not always how to do something. The following section of the Guide lays out an approach your coalition can take to prioritize, plan and get feedback about your access to cancer care initiatives.

10 Elements of a Successful CCC Coalition Access to Cancer Care Effort

This section of the Guide is designed to assist CCC coalitions with determining what they can do to address access to cancer care issues. Each of the 10 Elements includes considerations and key questions, as well as links to resources. The last section of the Guide includes five success stories and gives examples of how the some of the 10 Elements were used and contributed to the success of coalitions' access to care initiatives.

10 Elements of a Successful CCC Coalition Access to Cancer Care Effort



FOCUS IN ON THE ACCESS PROBLEM

Result: An access to cancer care problem supported by your CCC plan and coalition members.



IDENTIFY A CHAMPION

Result: An influential leader committed to the effort.



ASSEMBLE A TEAM

Result: An experienced, high energy strategy team.



DESCRIBE THE PROBLEM

Result: A focused, data-driven problem statement.



ORGANIZE AN APPROACH

Result: A plan of action to address the problem.



EXPECT and PREPARE FOR OPPOSITION

Result: An effective proactive and reactive response to opposition.



BUILD STRONG ALLIANCES AND WIDE-SPREAD SUPPORT

Result: Active support for your efforts by many individuals and organizations.



ALLOCATE RESOURCES TO REFLECT THE IMPACT DESIRED

Result: Dedicated money and/or staff to sustain the level of effort needed to achieve your outcomes.



ASSESS PROGRESS, BE CREATIVE AND FLEXIBLE IN YOUR EFFORTS

Result: An approach that is refined according to the challenges and opportunities that arise.



BE PATIENT AND PERSISTENT

Result: Success



FOCUS IN ON THE ACCESS PROBLEM

Result: An access to cancer care problem supported by your CCC plan and coalition members.

Of all forms of inequality, injustice in health care is the most shocking and inhumane.
Rev. Dr. Martin Luther King, Jr.

Considerations and Questions to Ask

Multitudes of complex issues can be identified as access to cancer care problems – identifying where to start can be overwhelming. It is overwhelming, but starting somewhere is better than not doing anything at all. Small successes can lead to bigger ones. Inaction leads nowhere. Choose to do something.

Your comprehensive cancer control coalition has gone through a significant process to identify data-driven and stakeholder driven priorities to include in your CCC plan. Validate the CCC plan and the coalition members by identifying an access to cancer care problem identified within the plan.

- What access to cancer care problems have been identified in your CCC plan?

Your CCC plan may have several access to cancer problems that are priorities. Coalition members may not know which problem to address first or there may be conflicting ideas within the coalition about the relative priority of the problems. Engage in a thoughtful discussion to assess the choices.

- What are your CCC coalition's strengths to address the issue?
- What are the major obstacles you anticipate you will encounter if you address this issue?

Access to cancer care issues are often complex and diverse. They can be found across the entire cancer continuum; they often involve many health care related systems; and they can require significant resources to address. As a starting point, it may be best to identify a smaller target goal that has high chance of success within the larger problem.

- What is the scope of the problem you want to address?
- If the problem is large and complex, what is reasonable to initially address?

From Oregon Cancer Plan

When asked to name Oregon's top three health care problems, Oregonians didn't name specific diseases. Instead, they said the leading problems are: 1) access to health care; 2) cost of health care; and 3) cost of health insurance.¹



IDENTIFY A CHAMPION

Result: An influential leader committed to the effort.

Leaders are visionaries with a poorly developed sense of fear and no concept of the odds against them. They make the impossible happen.

Dr. Robert Jarvik

Considerations and Questions to Ask

People who have been successful in an access to cancer care approach have indicated they had a “champion” that was instrumental in advancing their efforts.

Often a champion for an issue emerges from the coalition in a spontaneous and natural way. They may have a leadership role within the coalition, or are actively involved in a workgroup.

If you recruit a champion or one emerges; specifically ask them if they would be the leader for this effort. A clear understanding of their role and expectations is important for you, your coalition leadership and members, as well as the designated champion.

Key characteristics of a champion for an access to cancer care effort...

- Is **passionate** about the issue.
- Is **knowledgeable** about the issue.
- Has strong **networks and relationships** with stakeholders who can influence decisions about the issue.
- Is able to **devote time and energy** to the issue.
- Is **willing to work with others** on the approach.
- Is **respected and supported** by the CCC coalition members.

Who will be your champion for this effort?



ASSEMBLE A TEAM

Result: An experienced, high energy strategy team.

In Maine we waited for help from the federal government. Help to reduce the cost of health care, help for those without coverage and help to lower the cost of prescription drugs. We decided not to wait any longer.

Maine State Senator Michael Brennan

Considerations and Questions to Ask

Assemble a team to take ownership of the entire process from beginning to end. At this point, it is probable that a team that meets the needs of this specific access to cancer care effort does not exist. You may already have a workgroup or a sub-committee who has worked on this area in the CCC plan – some of them may belong on this new team, but some may not. Seriously consider developing a new strategy team that has been assembled for this specific effort.

You want top notch, high energy people who are willing to go the extra mile. Others who may be knowledgeable on the issue but aren't able to or aren't willing to work hard and persevere over the long haul are not the people to have on your strategy team.

You will and must include many people over the course of your efforts to assist with your approach – but the strategy team is different than your usual workgroup or sub-committee.

Suggested characteristics of the strategy team:

- A small group (4-6 people)
- Responsive when decisions need to be made quickly.
- Have a good sense of what decisions can be made by the team, and what decisions need to go to a larger group, like an executive committee or the full CCC coalition.
- Are guided by the values, guiding principles and trust of the CCC coalition in their actions and decisions.
- The team is actively involved – so they are up to date on the team's current efforts.
- They are accountable for getting the job done as a team.

With your coalition member list in hand and a group of 2-3 people who know most of the coalition members, begin to identify your team using these questions as triggers in your thinking:

People Who Have Past Experience in Similar Efforts

- Who has worked on this type of effort before?
- Who has influence with the organization or system you want to work with?

People with a Variety of Knowledge and Skills

Consider **technical** knowledge and skills, as well as the **type of work** people have a successful track record in.

- What **technical** background do we need (e.g. colorectal screening, health care insurance, hospice care)? Who has it?
- What **type of approach** do we think we are going to use (e.g., policy development, community mobilization, communication / marketing)? Who has experience in that?

People Who Work Well With Others

Identify people who are team players, are willing to consider other's views and can share their own experiences and opinions in a collegial manner.

Recruit Strategy Team Members

- Who is on your list?
- Ask them to be involved – and share with them the characteristics of the team and individual members listed above.
- Obtain their commitment – if they choose not to be a member of the strategy team, ask them if and how they would like to be involved in a different way.



DESCRIBE THE PROBLEM

Result: A focused, data-driven problem statement.

I don't see the logic of rejecting data just because they seem incredible.
Fred Hoyle

Considerations and Questions to Ask

Having and communicating credible information is powerful and critical for your efforts. Using data should be a strategy in your approach to make a change. Most people are compelled to take action when they see data that clearly illustrate a problem.

Gathering data, sifting through it and drawing conclusions is one of the most important steps you can take at the beginning of this effort.

Use the data to defend your statement of the problem and the approach you choose.

Find the data that are relevant and describe the problem and answers your questions. Be aware of collecting more data than is useful to you.

Identify the data that will help you:

- Understand the characteristics and dimensions of the problem.
- Apply peer pressure. Compare your situation to others who are “better off” than you are. For example if you are addressing a state issue – compare your state to other states and highlight the states “ahead” of you.

Determine the best format and audience to communicate the data and the problem to in order to build support for your efforts.

Gather together your data experts from the CCC coalition. Explain to them what problem you want to address and the need for data to clarify and communicate the problem. Use the chart below to guide your discussions and determine what other data to obtain and where to get it.

Types of Access to Cancer Care Data and Sources of Data

<p style="text-align: center;"><u>Availability - Examples of Types of Data</u></p> <ul style="list-style-type: none"> • Programs/services available across the continuum of care, gaps in services, availability of appropriate healthcare professionals, etc. • Inventories of cancer programs or services • Special studies re: gaps in services • Geographic distribution of primary care, gynecologists, urologists, oncologists and other specialists that provide cancer care; shortages data • Profile of public/private insurance coverage for evidence based services • Utilization data 	<p style="text-align: center;"><u>Examples of Data Sources *</u></p> <p>North American Association of Central Cancer Registries (NAACCR): http://www.naacr.org/ http://www.cancer-rates.info/naacr/</p> <p>Centers for Medicare and Medicaid Services (CMS): http://www.cms.hhs.gov/DataCompendium/01_Overview.asp#TopOfPage</p> <p>EDELE (Epidemiology of Dying and End-of-Life Experience) http://www.edeledata.org</p>
<p style="text-align: center;"><u>Accessibility - Examples of Types of Data</u></p> <ul style="list-style-type: none"> • Transportation issues, geographic location of services, alternative hours of care, transfer of medical information (e.g., patient charts), etc. • Geographic reach of local public health services, community health centers and other facilities 	<p style="text-align: center;"><u>Examples of Data Sources *</u></p> <p>Behavioral Risk Factor Surveillance System (BRFSS) http://www.cdc.gov/brfss</p> <p>National Cancer Data Base (NCDB) http://www.facs.org/cancer/ncdb/publicaccess.html</p> <p>NAACRR Great Circle Distance Calculator http://www.naacr.org/index.asp?Col_SectionKey=11&Col_ContentID=463</p> <p>Safety Net Monitoring Initiative http://www.ahrq.gov/data/safetynet/</p> <p>National Home and Hospice Care Survey http://www.cdc.gov/nchs/nhhcs.htm</p> <p>Health Information National Trends Survey (HINTS) http://hints.cancer.gov/</p> <p>The Robert Wood Johnson Foundation Community Tracking Study http://www.rwjf.org/pr/data.jhtml</p>

<p><u>Acceptability - Examples of Types of Data</u></p> <ul style="list-style-type: none"> • Insurance coverage, care for the underinsured/uninsured, etc. • Number/percentage of patients with health insurance • Number/percentage of patients with public insurance (Medicare, Medicaid, SCHIP) • Number/percentage of uninsured population • Cost/benefit data (C-Change report) 	<p><u>Examples of Data Sources *</u></p> <p>Consumer Assessment of Health Plans Study (CAHPS) https://www.cahps.ahrq.gov/content/ncbd/ncbd_Intro.asp?p=105&s=5</p> <p>MEPS—Medical Expenditure Panel Survey http://www.ahrq.gov/data/mepsix.htm</p> <p>Health Care and Insurance</p> <p>MEPSnet—Interactive Tool for Statistics on Health Care and Insurance http://www.meps.ahrq.gov/mepsweb/data_stats/meps_query.jsp</p> <p><u>HCUP—Healthcare Cost and Utilization Project</u> http://www.ahrq.gov/data/hcup/</p>
<p><u>Accountability - Examples of Types of Data</u></p> <ul style="list-style-type: none"> • Quality of services, care management, navigation programs, etc. • Patterns of care data • Number, location and scope of cancer services and programs 	<p><u>Examples of Data Sources *</u></p> <p>SEER-Medicare Datasets http://healthservices.cancer.gov/seermedicare/</p> <p>HCUPnet—Interactive Tool for Statistics on Hospitals http://hcupnet.ahrq.gov/</p> <p>Health Plan Employer Data and Information Set (HEDIS) http://web.ncqa.org/tabid/59/Default.aspx</p> <p>Breast Cancer Surveillance Consortium http://breastscreening.cancer.gov/</p> <p>HMO Cancer Research Network (CRN) http://crn.cancer.gov/</p>

* Some of these data sources address more than one of the types of cancer care issues.

With your strategy team and your data experts - answer these questions to help you decide what to communicate about the problem as well as what approach to consider:

- What does the data tell you about the problem?

- What type of problem does this appear to be?
 - Availability
 - Accessibility
 - Affordability
 - Acceptability
 - Accountability

- Where do you want to make changes? (This will help determine where to focus your efforts.)

- What ideas do you have about the approach to take based on the answers to the above questions?



ORGANIZE AN APPROACH

Result: A plan of action to address the problem.

Knowing is not enough, we must apply. Willing is not enough, we must do!
Goethe

Considerations and Questions to Ask

There are many examples of how others have approached access to cancer care issues. No one has found *the* best approach or everyone would be doing it! We can learn from others experiences, get ideas, and focus on critical components that have been proven successful – but in the end, the approach you take must be tailored and customized to meet your needs and unique circumstances.

Below is a list of key steps to customizing and organizing an approach to address your access to cancer care issue:

- **Seek out and ask** what others have done to address similar issues.
- **Think** about how you can apply their efforts to your situation.
- **Debate** how different approaches will or will not work for your circumstances.
- **Plan an approach** based on your findings and discussions.
- **Identify** the skills needed to be successful in your approach.
- **Share** your ideas and plans with others to get feedback and suggestions.
- **Revise** your approach. A good approach will take some time to develop.

The strategy team can address the key steps above by asking these questions.

- What kind of approaches are we considering?
 - Policy?
 - Program?
 - Practice?

Below is a chart that provides examples and resources to get ideas and learn more about what others are doing in policy, program and practice approaches to access to cancer issues.

Types of approaches and examples of actions	Resources for more ideas and examples of what others have done
<p><u>Policy</u> Advocating for legislative or regulatory changes that increase access for all, for example supporting state level health care reform efforts or mandated insurance coverage of colorectal cancer screening.</p> <p>Support for organizational policy changes that increase access, for example largest employer in the state expands coverage of clinical trials for employees.</p>	<p>The National Conference of State Legislatures http://www.ncsl.org/programs/health/h-primary.htm</p> <p>The National Academy for State Health Policy http://www.nashp.org/index.cfm</p> <p>Council of State Governments - Comprehensive Approaches to Cancer Control Toolkit http://www.csg.org/pubs/Documents/Toolkit05CancerControl.pdf</p>
<p><u>Program</u></p> <p>Enhancing or developing specific interventions to understand and/or solve problems, for example adding colorectal cancer screening to existing breast and cervical cancer screening.</p>	<p>The Robert Wood Johnson Foundation - Health Insurance Coverage http://www.rwjf.org/programareas/programarea.jsp?pid=1132</p> <p>Research Tested Intervention Programs (RTIPS) Survivorship Programs http://rtips.cancer.gov/rtips/rtips_search.do?topicid=12&choice=default&cg=</p> <p>Kaiser Family Foundation http://www.kff.org/about/kcmu.cfm</p>
<p><u>Practice</u></p> <p>Wide scale systems changes that improve delivery of care and increase access to services and may include policy and program solutions, for example within a region of the state hospitals, community health centers and the CCC coalition partner to develop a seamless system of education, screening, referral and patient navigation to increase breast, cervical and colorectal cancer screening. Another example is large employers in the state seek accreditation through the CEO Cancer Roundtable Gold Standard program.</p>	<p>The Health Disparities Collaborative http://www.healthdisparities.net/hdc/html/collaboratives.topics.cancer.aspx More information about the Cancer Collaborative can be found in the next section of this document.</p> <p>Coalition of Cancer Cooperative Groups – Clinical Trials http://www.cancertrialshelp.org/patientsCaregivers/patientsCaregivers.jsp</p> <p>CEO Cancer Roundtable Gold Standard http://www.cancergoldstandard.org/</p>

- What do we know about how others have gone about addressing this problem?
 - Use this guide as a resource to begin seeking out other's experiences.
 - Beware! There is so much information online that you can get confused and bogged down on what to do. Look to major organizations and agencies for summaries or best practice examples of what has worked or been tried.
 - Contact people in your network and ask them what they have tried, and who they know who has experience in this area.
- What is the current interest level regarding this problem of the decision makers and key stakeholders we would work with?
- Who are the key decision makers that we need to agree to and support our approach? What strategies / tasks do we put in our approach to get their support?
- Who are the key stakeholders we would work to implement our approach? What strategies / tasks do we put in our approach to get their support for implementation of the approach?
- How can the political environment (at the state, local or organizational level) help us or hinder us on our efforts? Have we taken that into account in our approach? Consider these types of questions: Is this an election year? Is the leader you are working with in an organization well supported and respected in their organization and community? Is there management and fiscal stability in the organization / agency with which you are working?
- Determine the type of information and the methods you will communicate with each other, the CCC coalition and the stakeholders who are involved or affected by your efforts. Does your approach have a communications / public relations aspect to it? If so, make sure you have someone involved who has these skills.

Develop a detailed plan of action that includes specific tasks, key stakeholders to involve, who is responsible for each task, timelines and resources needed. Seeing the overall approach on paper will help you identify any gaps in your approach and will assure everyone is moving in the same direction.



EXPECT and PREPARE FOR OPPOSITION

Result: An effective proactive and reactive response to opposition.

Anyone who proposes to do good must not expect people to roll stones out of his way, but must accept his lot calmly if they even roll a few more upon it.

Albert Schweitzer

Considerations and Questions to Ask

The larger your ideas and desire for change, the more prepared you need to be for strong opposition. You can expect that some people will not be fully supportive of your ideas and actions. They may think there is not a problem, or they have a different idea of how to address the problem. You can't ignore the opposition. The key is be prepared for it. And know when compromise is necessary.

Be prepared by brainstorming the arguments or opposition tactics you might be faced with. Then develop a plan to either pre-empt the issues or a plan to be prepared to address them when they are raised. Write down your rebuttal to each of the arguments you identified.

Contact others who have tried similar efforts and ask them what opposition they experienced and how they dealt with it – or how they wished they had dealt with it!

Determine who will be the “spokesperson” for the group. Who will speak if the group is needed to make a statement, or engage in a discussion with the opposition or there are inquiries about the effort. Usually the spokesperson is the champion of the effort. Agree who the spokesperson is speaking on behalf of, for example, the CCC coalition or the coalition and a larger group of stakeholders?

Remember any public communication should be focused on a main message about the problem you are trying to solve, and simple messages about your approach to solve the problem.

Often those opposing an effort to increase access to cancer care do not oppose your goal to improve a situation. But money, turf issues, politics and control are the real issues. Figure out if there are solutions to deal with those issues.

The vast majority of people you are working with want to make access to cancer care a reality. How that goal is achieved is what takes a lot of negotiation and patience.



BUILD STRONG ALLIANCES AND WIDE-SPREAD SUPPORT

Result: Active support for your efforts by many individuals and organizations.

Let us put our minds together and see what life we can make for our children.
Sitting Bull

Considerations and Questions to Ask

Involve everyone you can think of to get support for your effort. Instill a sense of ownership of the effort in each of these groups by asking them to play a specific role where it is appropriate in your approach you have outlined.

Types of roles to consider:

- **Communication** of their support to the public or their key constituents.
- **Contribution** of resources of money, staff, equipment, etc.
- **Advocacy** efforts such as attending public or organizational meetings, making phone calls to key decision makers, opinion editorials, etc.
- **Provide** data, reports or other information to build your case and support your approach.
- **Written commitment** to a plan to make a change in their organization or system.

Think about the specific role / tasks for each of these stakeholders, and ask them to engage in that role!

- The CCC coalition leadership
- The CCC coalition members
- CCC national partner organizations
- The public
- Cancer patients, their families, survivors

- The media
- Health providers and their local, state and national associations
- Health care systems, such as hospitals, cancer centers, community health centers, physician groups
- Insurers
- Policy makers / elected officials
- State agency leaders

Involving these stakeholders in a meaningful way and communicating with them is **essential** to your success! Do this by:

- Asking them for specific things that are reasonable so they will most likely say “yes” to your request.
- Ask them how they would like to be involved.
- Share with them frequent communications about efforts, progress and milestones.
- On a regular basis let them know you need them, appreciate what they done thus far, and ask for their continued support. You can do this either by short meetings or phone calls (not an email!)



ALLOCATE RESOURCES TO REFLECT THE IMPACT DESIRED

Result: Dedicated money and/or staff to sustain the level of effort needed to achieve your desired outcomes.

Don't tell me where your priorities are. Show me where you spend your money and I'll tell you what they are.

James W. Frick

Considerations and Questions to Ask

Resources to support your effort are important and may be a sizable need.

Consider these resource needs:

Staff: You've got a CCC coalition and a strategy team made up of volunteers. How much can you ask from them? How much can you expect? A key learning from those who have had successful access to cancer care efforts is having a paid staff person(s). This person(s) is charged with making sure that progress is being made on the effort and action plan, that issues are identified in a timely and efficient manner, that day to day operational needs are addressed, and that significant dedicated time is given to the effort. Usually this person is knowledgeable and has experience and skills in the area of the effort.

Developmental and Implementation Resource Needs: Will your effort require reports, public education materials or training manuals, equipment, expert consultant time, media, transportation costs? Just like any effort, developing a budget that clearly shows your needs is a necessary task to understand what it is going to take to get the job done.

Length of Time Needed for Resources: Determine how long you will need these resources. Is the effort designed to be institutionalized after a period of time? How long do you anticipate that it will take before it is? How long will you need a staff person for the effort?

Consider these options for meeting your resource needs.

Contributions from CCC Coalition Members

Sharing the budget you've created with the CCC coalition or specific members of the coalition can initiate the conversations of who may be able to contribute specific resources to the effort. A shared resourcing strategy that has multiple CCC coalition

organizations contributing to the effort in a variety of ways may be the most realistic way to obtain what you need to get the job done.

Searching Out Other Funding Opportunities

Ask others in your network where they have obtained resources to do this type of work. They may give you ideas about foundations, organizations or associations or fund-raising opportunities that you hadn't thought of.

Overcome Fiscal Barriers By Thinking Outside the Box!

If directly obtaining resources is a fiscal operating issue for your CCC coalition, can another organization be the fiscal agent for resources obtained for this effort? Can a member organization hire (either with their funds or with other resources) a staff person to work on this effort? Ask the CCC coalition and your stakeholders to think about solutions to these barriers. When challenged with a problem, you may be surprised what people come up with as a solution.

Remember, the amount of resources you are willing and able to give to this effort will most likely have a direct effect on the progress you will make towards your outcome.



ASSESS PROGRESS, BE CREATIVE AND FLEXIBLE IN YOUR EFFORTS

Result: An approach that is refined according to the challenges and opportunities that arise.

No problem can stand the assault of sustained thinking.
Voltaire

Considerations and Questions to Ask

Whether your effort is a program, policy or practice effort, an evaluation plan is a must to demonstrate the impact it has on the problem you want to address. Most CCC coalitions have an evaluation plan for their CCC plan's priority strategies. Is your access to cancer care effort a part of that evaluation plan? Share your detailed plan of action with those that are responsible for evaluating the CCC coalition plan. They can help you with determining what you should be evaluating in your efforts and how to put methods and measures in place to assure a strong evaluation component.

As you have most likely already experienced in your CCC coalition, when you start to implement your CCC plan, you rarely get the luxury of "smooth sailing". Unexpected challenges can arise at anytime. A partner organization changes their mind about being involved. A proposed bill in the state legislature gets altered at the last minute. Key stakeholders you rely on change jobs or move to a different organization. The new data reports are not what you expected. And so on and so on! You must regroup, review and revise your plan of action.

Key questions to ask when you are faced with "things are **not** going as we planned" include:

- What is the problem? Do the "5 whys" exercise with your strategy team (identify the problem and ask why 5 times to get to the root of the problem).
- How large is this problem? Is this a bump in the road you need to get over – or could this problem derail your efforts completely? Talking about the specifics of the problem will get everyone on the same page about its seriousness and what to do.
- Avoid personalizing the problem to a person, or a specific organization. You will always have people who say, do, or behave in ways you don't agree with. Focus on solutions that will move your efforts forward. One of your solutions may be to involve the person or organization in your problem solving.

- Brainstorm solutions to address the problem. Which of these solutions does the strategy team think is the approach most likely to resolve the problem at hand?
- Ask if the problem and the solution to the problem are too big of a compromise to your desired outcomes. You may have to decide you need to compromise and that some success is better than no success. Or you may decide that the problem is not insurmountable and requires an ongoing, determined effort along the lines of what you had planned.
- Involve your CCC coalition leaders, members and key stakeholders in discussing larger problems. They will want to be involved and can offer suggestions for a solution. If hard decisions need to be made, their involvement up front will provide support for your actions later.
- Communicate to your stakeholders any decisions that affect their work with you.
- Determine how the solution will be implemented.

When you are successful – celebrate your success! Make sure **everyone** knows. You can leverage widespread communication about your success to move forward with other efforts!



BE PATIENT AND PERSISTENT
Result: Success

Fall seven times. Stand up eight.

Japanese proverb

Considerations

Access to cancer care problems are complex problems. They are not easy to solve, nor will they be solved quickly.

Most approaches to address an access to cancer care issue require the active involvement of many people and personalities, diverse organizations, and separate and often competing agendas. Developing functional, trusting and reliable relationships and sound approaches with adequate resources takes time and you'll often encounter setbacks.

At times it may feel like your time and resources might be better directed somewhere else. Hang in there. Keep your eye on the big picture of what could be accomplished.

And remember, if you fall seven times, stand up eight.

Increasing Access to Care: Six Success Stories

Through C-Change's efforts to collect information regarding current CCC coalition activities to address access issues, a small number of initiatives were selected to highlight in this guide. Each of the six examples below represents innovative and successful efforts to tackle access issues.



1 Arizona: Better Access to Breast Cancer Screening Services for American Indian Women

Laying the Foundation: Policy Change

In 2002, Arizona voters passed Proposition 303 which increased the state tax on tobacco products. Two percent of the tobacco revenues were earmarked for chronic disease programs at the AZ Department of Health Services, including cancer, heart disease, stroke and pulmonary disease. The Tobacco Revenue Use Spending and Tracking (TRUST) Commission provides oversight for Prop 303 allocations and spending. In 2006 Arizona's National Breast and Cervical Cancer Early Detection Program, the AZ Well Woman HealthCheck Program (WWHP), was awarded \$250,000 by the TRUST to decrease breast cancer mortality rates in the state.



Through the combined leadership efforts of the WWHP and the AZ Cancer Control Coalition, the decision was made to use some of the funds to target efforts toward increasing breast cancer screening rates among American Indian women in Phoenix. The WWHP and the Coalition were already working together and had identified access to breast cancer screening services as an issue for American Indian women in the area.

Focusing in on the Problem



The WWHP began a pilot project with the Phoenix Indian Medical Center (PIMC) to implement and enhance the WWHP at the Center. The unmet needs related to breast cancer screening at PIMC were clear: A one to two year waiting list for women to be seen for annual exams was identified as contributing to the low screening rates. PIMC's data showed mammography rates for women 52-64 at 42%, and the rate for pap smears for women 21-64 at 63%. Approximately 5,000 women within the PIMC system were identified as eligible for the WWHP. In addition, PIMC patients did not want to leave their "medical home" and PIMC's system for managing existing abnormal results was overburdened. The WWHP realized they would need to provide more support and technical assistance to PIMC to get them up and running Center-wide as a WWHP provider.

The Solutions

Through intensive technical assistance (regarding reimbursement and clinical review), ongoing training (regarding reimbursement, collecting patient information and billing) and committed leadership on both sides, the pilot project at PIMC has been a success. PIMC estimates that they have doubled the number of women they now screen through the WWHP. In addition, more American Indian women are accessing treatment funds through the AZ Medicaid treatment

program than before. The success of the pilot project has been communicated to other Indian Health Service clinics in the state and there is interest in expanding the program.

The Outcomes

While there will be additional challenges ahead for the pilot program and its expansion, the AZ Cancer Coalition partners have proven that they can improve access to screening services, and better utilization of Medicaid treatment funds, for American Indian populations in the state. As of August 2007, 1 breast cancer and 1 cervical cancer were identified through the newly enhanced WWHP clinics at PIMC and linked to the breast and cervical cancer treatment program.

There is a systematic evaluation process in place to better understand what is working and not working during the pilot.



And last but not least, the acquisition of resources through Prop 303 is also a major success. While the CCC coalition was not solely responsible for the tobacco tax initiative they have greatly benefited from the existence of the TRUST funding. The CCC program has received approximately \$1 million for a colorectal cancer screening awareness campaign and an additional \$1 million for a colorectal cancer screening program. The screening program is slated to begin in 2008. The experiences of the WWHP in breast and cervical cancer screening will be an asset as the coalition focuses on designing a colorectal cancer screening program.

Lessons Learned

Key to the success of the pilot project is the strong relationship between partners. Leaders from the WWHP and PIMC are members of the AZ Cancer Coalition and serve on the Coalition's Early Detection Team. A champion in the effort is the Associate Director of PIMC and current chair of the Coalition, Dr. Charlton Wilson.

A lesson learned for the WWHP is that it takes more time and resources (staff time and on-site technical assistance) to carefully implement the WWHP within the I.H.S. system. Shared accountability and patience are and will pay off in the end.

② Colorado: Resources and Partnerships for Colorectal Cancer Screening



Policy Change Leads to Unprecedented Resources for CCC

In November, 2005 Colorado voters passed an increase in the state's tobacco excise tax through Amendment 35. Portions of the revenue are directed to programs within the Colorado Department of Public Health and Environment. Sixteen percent of the revenue is directed to tobacco education programs. An additional sixteen percent is directed to the prevention, early detection, and treatment of cancer, cardiovascular and pulmonary disease through a competitive grants program and expansion of the Colorado Women's Cancer Control Initiative for breast and cervical cancer screening program. Approximately \$3,785,367 in grants

went to cancer prevention and control or programs that include cancer control as part of the program during FY 05-06. Colorado was the first state in the nation to achieve such a level of successful advocacy for implementation of CCC plan strategies.



Building on Strengths: The CCC Plan and Partners

With a cancer plan that made a strong case for increasing the utilization of and access to colorectal cancer screening in Colorado, a committed group of over 25 partners who agreed to be champions for the issue, and a source of funding, the Colorado Cancer Coalition set out to build a comprehensive colorectal cancer education, prevention and screening program for the state.



The cancer plan clearly laid out the issue: Utilization of proven colorectal cancer screening modalities was low, even within the insured population; too many Coloradans did not have adequate access to screening, diagnosis and treatment services. The access issues ran the spectrum, from availability through accountability. The solution was the development of a multi-faceted program to increase screening rates, improve quality of care, increase capacity of providers to offer services and raise awareness among the public about the need for colorectal cancer screening.

The driving force behind the effort was and continues to be the Coalition's Colorectal Cancer Task Force. The Task Force is a partnership of over 25 organizations and individuals from multiple disciplines, dedicated to saving lives through efforts to prevent colorectal cancer. The primary focus of this task force is prevention. With current and future strategies the goal of the Task Force, as reflected in the Colorado Cancer Plan, is to screen 75% of the eligible population in Colorado.

The Outcome: A Comprehensive Screening Program

Through the efforts of the Task Force, the Colorado Colorectal Screening Program was established with Amendment 35 grant funds and is lead by the University of Colorado Cancer Center to provide colorectal cancer screening services to medically underserved Coloradans. The program provides endoscopic colorectal screening to Coloradans ages 50 and older (average risk) or under 50 at moderate or high risk for colon cancer (personal or family history). In addition to the Screening Program, other complementary colorectal cancer projects ensure wide scale delivery of the message that colorectal cancer screening is important. Some of these include:

- The Colorado Colorectal Cancer Screening Awareness Project aimed at increasing endoscopic screening rates among all Coloradans aged 50 – 74. This is a multi faceted intervention with support from many partners including the state health department, the University of Colorado School of Medicine, insurers and medical providers. This project is funded by the Centers for Disease Control and Prevention, through the Comprehensive Cancer Program.
- Screen the Screener is a Colorado Comprehensive Cancer Program project launched in the spring of 2006, funded through Colorado Department of Public Health and Environment, the Centers for Disease Control and Prevention, and the University of Colorado Cancer Center. This program is designed to encourage health professionals to

promote colorectal cancer screening and send the message that colorectal cancer screening is a priority. Screen the Screener is an opportunity for mid level providers, doctors, nurses, medical assistants and front office staff who may play a role in promoting and facilitating endoscopic screening to be screened themselves. American Cancer Society and others have provided education materials to providers to be used in their office settings to encourage patients to be screened. Nearly 200 physicians have been screening through the program.

Lessons Learned

Early on, the keys to success for the tobacco tax initiative included the formation of a special partnership to lead the tax initiative, called Citizens for a Healthy Colorado. The Colorado Cancer Coalition was one of many organizations to join this partnership which was developed solely to pass the tax increase. Once the funding was earmarked for cancer programs, the Colorado Cancer Coalition's taskforces mobilized to develop grant requests for their priority cancer plan strategies. A key to the Coalition's advocacy success was breaking the budget for the cancer plan down into smaller chunks. The full budget was too daunting but cancer specific funding seemed doable to legislators and other key proponents.

A lesson learned in the budgeting process was that time and effort spent on tracking Coalition members' in-kind contributions was important as the Coalition leadership approached policy makers for the cancer program funding. The ability to show \$11 million in-kind from partners made the difference by showing that the Coalition and its priorities were important enough to warrant support and it showed that there would be other resources to help sustain the programs overtime.



Keys to success related to the Colorado colorectal cancer initiative include:

- Outreach to GI community and existing public health providers to convince and encourage them to be supportive of the screening program, since it may have been seen as another burden on their time and resources. The Colorectal Cancer Task Force was responsible for building these relationships.
- Using data and key messages already developed about colorectal cancer was valuable. For example, Colorado participated in the CDC sponsored SECAP study so they had a good understanding of the capacity to provide endoscopic services in the state.
- An earlier Dialogue for Action around colorectal cancer brought the key partners together to develop solutions together and this served as the impetus for developing a comprehensive approach to the issue of colorectal cancer.

③ Delaware: Increasing Access to Cancer Care for All People



Eliminating Treatment Barriers

In 2004 Delaware became the first state in the nation to provide free cancer treatment for those who meet eligibility requirements. The Delaware Cancer Treatment Program covers people with a household income that is less than 650% of the Federal Poverty Limit. As of July 2007, treatment eligibility was extended from 12 to 24 months from the date cancer treatment is started.

From July 2004 – June 2007, 348 Delawareans have been served. Applicants are equally distributed male and female. Minorities are overrepresented among those served with 26% being African American, 9% Hispanic, 3% other and 62% Caucasian. One third of those served are between the ages of 50-59. Twenty percent are 40-49 years of age and 18% are 60-64 years of age.

The average expenditure by case is \$33,525 which is consistent with national data on cancer treatment expenditures. Since program inception approximately \$11.7 million was spent to provide treatment services through the program.

In addition to the Cancer Treatment Program, three other innovative initiatives are supported with state funding to increase access to cancer care:

- **Cancer Care Coordinators:** To ensure that every cancer patient in Delaware has an advocate, the Delaware Cancer Consortium (DCC) has placed cancer care coordinators in all health systems throughout the state. Care coordinators help cancer patients navigate their way through the health care system to make sure that each patient gets the care and services they need. There is no fee to Delaware cancer patients. In 2006, the Care Coordinators were able to assist approximately 836 patients.
- **Screening Nurse Navigators:** Because people have a greater tendency to get screened if someone else helps them through the process and follows through, the DCC has hired registered nurses in five health systems who offer their assistance free of charge to Delaware residents. The screening coordinators serve as community ambassadors, delivering the message about the need for colorectal cancer screenings on a regular basis. They also attend community events, provide information on Screening for Life, the breast, cervical and colorectal cancer screening program in Delaware, and gather data on individuals who should be tested. In addition, they follow up with individuals who have registered with them to guide them through the process.
- **Champions of Change Outreach Program:** In Delaware, African Americans have a higher death rate from colorectal cancer than whites. The DCC has developed a community outreach program to increase screenings for and early detection of colorectal cancer. A tool kit that includes informational literature, brochures and an idea binder is available, free of charge, to organizations that wish to spread the word of the need for Delaware's African Americans to get tested for colorectal cancer. The Consortium is working to expand the Champions of Change Program to encompass not only colorectal cancer but prostate, breast and cervical cancer as well.

Supporting the Programs

The Delaware Department of Public Health (DPH), with support from and in partnership with the members of the Delaware Cancer Consortium, is responsible for managing these programs. The funding, approximately \$16.2 million in fiscal year 2008, comes from the Delaware Health Fund (tobacco excise tax). DPH manages the treatment program and has contracts with the hospitals to house the care coordinators and screening coordinators.

Identifying a Champion



Since 2001, Governor Ruth Ann Miner has been a champion for the Delaware Cancer Consortium and was instrumental in putting cancer on the political agenda in the state. She has been the driving force for laying a foundation to improve access to cancer care in the state.

The Consortium's committees are actively involved in guiding and supporting the access programs. They are high level officials, many appointed by the Governor, who are influential advocates and champions for the work of the Consortium. They are the "vehicle" for getting the support needed to implement the cancer plan.

Lessons Learned



The key to success in Delaware has been the identification and engagement of strong champions, like Governor Miner. A second critical lesson learned is the important of a long-term plan with measurable outcomes. The four-year cancer plan in Delaware, *Turning Commitment into Action*, has been the roadmap for the development and implementation of the cancer programs. Input from cancer survivors and family members are also crucial. Programs such as the Delaware Cancer Treatment Program were developed as a direct result of patient input.

④ Massachusetts: Increasing Access to Quality Colorectal Cancer Screening

The Massachusetts Comprehensive Cancer Control Coalition (MCCCC) has partnered with MassPro, the state's quality improvement organization, to train physician advisors to work with high and low tech practices to assess and develop sustainable changes that institutionalize systems to increase colorectal cancer screening.



The Pilot Program

Components of the program include patient identification, education, physician counseling, methods of ensuring screening, documentation of follow-up, and referral. This is a pilot project that began in 2007; currently 33 practices are participating. Plans are in place to expand the program to 300 practices in 2008. A practice assessment tool and tool kit have been developed and a risk management/quality improvement CME/CEU module to be delivered via web conferencing will be tested and become available nationally.

Practices participating in this quality initiative may also enroll in the “pay for quality performance” (P4P) demonstration project with CMS. CMS will pay providers at a higher rate when they increase their rate of CRC screening.

MassPro and the MCCCC are considering expanding the quality improvement program to Commission on Cancer accredited hospitals in the next phase of the pilot.

Lessons Learned



Leadership and thoughtful planning have been the keys to the success of the access to quality colorectal cancer screening project. The Massachusetts Colorectal Cancer Working Group is a long-standing partnership that actually pre-dates the MCCCC coalition. Dr. Paul Schroy serves as co-chair of the MCCCC Leadership Team and is also the chair of the Colorectal Cancer Working group. His leadership has been instrumental in focusing attention on the issue of increasing access to colorectal cancer screening. Recently the MCCCC sponsored a Dialogue for Action on colorectal cancer which helped program partners and participants focus in on the problems and potential solutions associated with providing quality colorectal cancer screening in the state.

The MCCCC has identified some lessons they have learned in establishing a pilot program. They are:

- Make the solution fit the setting when it comes to changing physician practices. Often times the technology changes that are part of the quality improvement program were too complex for smaller primary care clinics. The flexibility and resources to adapt the technology to the practice setting is vital.
- More time is needed to plan for a pilot project of this nature.



5 Wyoming: Advocacy for CCC Resources and Increased Access to Colorectal Cancer Screening



The Problem

The data are clear: In Wyoming colorectal cancer is the 2nd leading cause of cancer-related death. When detected early, it is known that colorectal cancer can be treated successfully. However; according to the Wyoming Behavioral Risk Factor Surveillance System Survey, only 48.5% of Wyoming men and women report ever having had a sigmoidoscopy or colonoscopy.



An Action Plan to Increase Support and Resources

To increase access to colorectal cancer screening, an action plan was created by a dedicated group of partners within the Wyoming Comprehensive Cancer Control Consortium (WCCCC). This group is now known as the “Colorectal Cancer Task Force”. The action plan was a comprehensive plan which included education to policymakers, advocacy efforts, public presentations surrounding colorectal cancer and the need for population-based screening, and training in “lobbying” for various WCCCC members. The Wyoming

affiliate of the American Cancer Society was a partner in providing leadership, education, and to the WCCCC for this effort. Their involvement would prove to be a key to success in getting the members of the WCCCC prepared to tackle the advocacy efforts that lay ahead.



One resource the WCCCC and ACS made use of during the legislative session was a fact sheet they prepared using compelling statistics from the Kaiser Family Foundation regarding uncompensated care costs in the state and nation. This information allowed them to build a “business case” for colorectal cancer screening.

The fact sheet is included in **Appendix B**.

The process began with an Op Editorial provided by the WCCCC Chairperson, WY Senator Eli Bebout, requesting that the Wyoming cancer plan no longer sit on a shelf, but be implemented at adequate funding levels. This caught the attention of WY Senator Charles Scott, Chairperson for the Joint Labor Health and Social Service Committee. Sen. Scott drafted a bill with the input of the WCCCC Steering Committee.

During the 2007 General Session, the WCCCC was highly visible with repeated activities at the state capitol. This included displays, cancer control materials provided to legislators, copies of the state cancer control plan available to policymakers, and an entire day dedicated to cancer control called the “Annual Celebration of Hope”. This was the second consecutive year the celebration has occurred. Important Wyoming leaders, such as the Department of Health Director, and the Governor of Wyoming, were in attendance.

The Outcomes

The Wyoming Cancer Control Act was passed almost unanimously in both houses and appropriated approximately \$1.4 million for the creation and implementation of the Wyoming Colorectal Cancer Early Detection Program (WCCEDP). This program provides colonoscopies to Wyoming men and women who are at or below 250% of the Federal Poverty Level and meet certain program criteria. To date, 15 counties are conducting screening.

In addition, funding enhancements for the Wyoming Breast and Cervical Cancer Early Detection Program were allocated (including a Native American breast and cervical cancer outreach program), as well as the authorization to implement a statewide pain committee. Total appropriations allocated in this act were \$1.860 million.



By far the greatest accomplishment was the creation of a line item in the state general fund for cancer control initiatives that can be expanded and measured over time. This was truly a win for Wyoming’s cancer control efforts.

Lessons Learned

Some critical lessons learned for the Health Department staff during the push to get the Act passed include:

- Understanding that it is ok for health department employees to provide education and answer questions throughout an advocacy initiative, so long as they do not “lobby” (a fact sheet used to guide health department employee actions is included in **Appendix B**).

- The staff gained a better understanding of the legislative process and the need for flexibility and nimbleness in reacting to changes, as well as responding to the opposition in a swift and professional manner. On another note, the bill that goes into the legislative session may not be the same when it comes out and often health department staff are the most knowledgeable partners when it comes to educating legislators and their staff about the infrastructure needed to support a public health program, such as the colorectal cancer screening program.

The following example, while not specific to a CCC coalition, provides an example of how local community partners can be involved in innovative practices to increase access to quality care. This example describes a successful program that CCC coalitions could replicate in their own communities.

⑥ The Cancer Collaborative: An Opportunity for CCC Coalition Action

A National Effort to Increase Access through Quality Delivery of Care

The Health Resources and Services Administration (HRSA) provides funding to over 1,000 health center grantees with over 4000 delivery sites across the United States and U.S. territories that serve more than 15 million medically underserved people, and who are predominantly members of racial and ethnic minority (64%), low-income (92%), Medicaid (35%), and uninsured (40%) groups. The Cancer Collaborative was designed to drive organizational change within health center practices such that coordinated and supportive cancer screening (specifically breast, cervical and colorectal cancers) and follow-up occur in a predictable, timely fashion.

At the present time, over 90% of health centers have been trained in the collaborative approach to service delivery transformation. From the Cancer Collaborative Pilot, improvements in care processes span the spectrum of activities that occur from providing patient education and screening services to ensuring that patients receive appropriate treatment for abnormal findings and providing further follow up. Many lessons for “planned cancer screening” have been learned through the collaborative and a framework has been established for implementing systematic changes in care that increase the effectiveness of screening efforts across the HRSA-supported health centers.

As a consequence, beginning in 2008, all health centers will begin systematically tracking and working to improve cervical cancer screening for health center patients. The long-term goal of this project is to track other cancers and to eliminate health disparities by closing the gap between the level of screening and follow-up in the general U.S. population, compared to those served by HRSA-supported health centers, and in so doing, reduce cancer mortality.

Additional information and materials about the Cancer Collaborative can be found at:
<http://www.healthdisparities.net/hdc/html/collaboratives.topics.cancer.aspx>

The Northeast Regional Cancer Collaborative

In 2005 HRSA, the Centers for Disease Control and Prevention and the National Cancer Institute developed a regional Cancer Collaborative in the northeast to further test the cancer collaborative model, on a regional level, and to assist selected Federally Qualified Health Centers (FQHC) with increasing screening rates for breast, cervical and colorectal cancers. Four FQHC's (many with multiple care delivery sites) were identified to participate. A "care process leader" was trained in each FQHC to lead site-based teams through the improvement process, common outcome measures were identified to report and track progress and each FQHC was encouraged to develop a local "community of practice" (i.e. a partnership of key local stakeholders) to help support community screening. Throughout the project national and regional faculty helped support the regional and local efforts.

The Outcomes

At the end of the year long project all four FQHC's had created "change teams" and implemented changes (for example patient reminders, standing orders, reorganized staff roles and clarified processes that better supported screening) in the way care is delivered resulting in increased tracking capabilities and increased screening rates for all 3 cancers, with the biggest increase in screening for colorectal cancer. In addition, 3 out of the 4 FQHC's created local communities of practice which led to an increased awareness of the needs in the community related to increasing access to cancer screening and new collaborative initiatives among partners, such as community screening events and resources for treatment.

On the regional level the implementation of the project resulted in a forum for sharing across states, including ideas about how to build local communities of practice.

Lessons Learned

Some lessons learned through the regional Cancer Collaborative include:

- At the FQHC level organizational commitment and leadership is key to successfully implementing the Collaborative Model
- It is important to have credible leaders at the local level when building local communities of practice
- Putting common measures of practice improvements in place (that were based on national measures) at the beginning of the process is critical
- A key tool at the FQHC is a good data system that is flexible and supports automated data entry
- A key partner contributing to the success at the regional level is the primary care association



The potential for CCC program or coalition involvement in a regional or local Cancer Collaborative is great. At the end of the Northeast regional Cancer Collaborative the regional "community of practice" ceased to exist; however, the local communities of practice continued. CCC coalitions could support and sustain these efforts at the regional or local level and implement their priority cancer plan strategies aimed at increasing access to quality cancer screening.

Other Successful CCC Coalition Activities to Increase Access to Cancer Care

Additional information about current CCC coalition access to cancer care activities can be found in **Appendix C** of this guide. As part of the process of developing the guide C-Change invited all CCC coalitions to submit information regarding their current access initiatives. A table outlining their submissions and contact information for each is included in the Appendix. The table also includes contact information for the five examples outlined above.

Appendices

- A. Comprehensive Cancer Control National Partnership:
Collaborating to Conquer Cancer**
- B. Wyoming CCC Example: Costs relating to CRC Treatment**
- C. Table of CCC Coalition Efforts to Increase Access to Cancer Care**

Appendix A

Comprehensive Cancer Control National Partnership: Collaborating to Conquer Cancer

Comprehensive Cancer Control National Partnership: Collaborating to Conquer Cancer

Comprehensive Cancer Control (CCC) is a collaborative process through which a community pools resources to reduce the burden of cancer, resulting in:

- Reduced cancer risk
- Earlier detection of cancer
- Better treatment
- Increased quality of life

American Cancer Society

American College of Surgeons Commission on Cancer

The CCC National Partnership

- For the first time in history, the ten leading cancer organizations have joined together to actively build capacity for cancer control at state, tribal, territory and local levels.
- CCC National Partners have leveraged resources and coordinated cancer expertise to collectively support CCC, as no one organization could do alone.
- The Partnership is an influential group of organizations that utilize their strengths among the cancer community to change the trajectory of the cancer burden in the US.

C- Change

Centers for Disease Control and Prevention

Major National Partners Initiatives

- Comprehensive Cancer Control Leadership Institutes for states, tribes, territories and U.S. Pacific Island Jurisdictions - A forum to learn, share and expand CCC efforts
- Planning Assistance Team Visits – Tailored on-site assistance for CCC coalitions
- Cancer Control P.L.A.N.E.T. (Plan, Link, Network with Evidence Based Tools) (<http://cancercontrolplanet.cancer.gov>) – An online data and planning tool
- CancerPlan.org (www.cancerplan.org) – An online resource for CCC programs and coalitions

Intercultural Cancer Council

Lance Armstrong Foundation

CCC National Partnership Success

- By 2006 every state in the nation had created a CCC plan. In 2001 there were only a handful of states that had cancer plans.
- Initiatives of the National Partnership have enabled states, tribes, territories and U.S. Pacific Island Jurisdictions to develop and begin to implement CCC plans.
- Together the National Partners have increased visibility and credibility for individual Partners' organizational efforts.

National Association of Chronic Disease Directors

CCC National Partners Link with CCC Coalitions across the Nation

- CCC coalitions represent an engine of change in the US for cancer issues. The National Partnership has used their power to convene these state, tribe, territory and local leaders and is committed to continue to work with CCC Coalitions across the nation to effectively address cancer issues.
- Through feedback and communication, CCC Coalition priorities are aligned with national priorities.
- As CCC Coalitions implement CCC plan strategies, they affect change such as:
 - Increased cancer screening rates
 - Increased access to treatment
 - Enhanced collaboration among cancer organizations
- Future National Partnership priorities include:
 - Fostering implementation and evaluation of CCC plans at the local level
 - Identification and support of policy initiatives that impact the burden of cancer
 - Assisting CCC coalitions with securing resources to implement their cancer plans

National Association of County and City Health Officials

North American Association of Central Cancer Registries

Moving Forward

- We now have the infrastructure, network and capacity in place to advance our continued efforts.
- Continued and increased support is needed to sustain the success of the CCC National Partnership and CCC coalitions.

National Cancer Institute

Appendix B

**Wyoming Tools:
Colorectal Cancer Fact Sheet
Education versus Lobbying Fact Sheet**

Wyoming Fact Sheet

Costs Related to Colorectal Cancer Treatment

Direct Medical Cost of CRC:

The average direct medical costs for CRC are \$35,000-\$80,000 per episode.

Early State Treatment vs. Late Stage Treatment:

When detected early, individual treatment costs for colon cancer is estimated at approximately \$30,000 for a patient.

The treatment for an individual who has developed late stage CRC is estimated at \$120,000.

The costs of uncompensated care:

- Most uncompensated care dollars are incurred by hospitals, where services are most costly
 - In 2001, hospitals accounted for over 60% of uncompensated care dollars.
- The primary source of funding for uncompensated care is government dollars!
 - In 2004, 85% of total uncompensated costs were covered by government entities.

(Kaiser Commission on Medicaid and the Uninsured, *The Cost of Care for the Uninsured: What Do We Spend, Who Pays, and What Would Full Coverage Add to Medical Spending?*, Issue Update, 2004)

A Business Case for CRC Screening:

For every 1,000 Wyoming people screened, we could potentially prevent 500 cancers via polyp removal. Within this same example, approximately 20 invasive cancers (adenomas) could be detected.

What does this mean in \$ and ¢ for Wyoming?

For early stage colorectal cancer, the cost to treat is approximately \$30,000. Because the state pays approximately 85% of that cost in uncompensated care for the uninsured, the state pays approximately \$25,500 per uninsured cancer case.

For late stage colorectal cancer, the cost to treat is approximately \$120,000. The state would end up responsible for \$102,000 per uninsured cancer case.

If we remove polyps in just 500 of the 1,000 screened via the program (which would prevent them from ever becoming cancer), we could see a potential cost savings of \$12,750,000-\$51,000,000.

If we identify just 20 adenomas, we still see a potential savings to the state of approximately \$510,000-2,040,000.

The Wyoming CRC Screening Program could potentially see a 25.5% return on our initial investment! (\$510,000 / Approx. \$2 mil)

If we can prevent just 17 cancers a year, we will have paid for the program (\$120,000 * 2,040,000). **Now that makes business sense!**

Education vs. Lobbying: Knowing the Difference

There are distinct differences between lobbying and education. It is important to know when one is providing information and when one has stepped into lobbying. Lobbying can be direct or grassroots:

- **Direct lobbying** is any effort to influence legislation through communication with any member or employee of a legislative body, or with government official or employee who may participate in the formulation of legislation.
- **Grassroots lobbying** is any attempt to influence any legislation through an attempt to affect the opinions of the general public or any segment of the general public.

In other words, **direct lobbying** is the time that you spend **persuading a legislator** to act or not act and **grassroots lobbying** involves **persuading other people** to contact legislators.

You are NOT lobbying if:

- You provide general information. Anyone can educate decision-makers and citizens about the importance of policies, legislative or budget issues. For example, let's say a bill is proposed that would lower the legal age to purchase alcohol to 18 instead of the current 21 years old. Data from the 2003 KIDS COUNT show that motor vehicle accidents are a leading cause of death for teens ages 15 to 19 years old in this state. National data show that nearly one-third of motor vehicle deaths of teens involved alcohol. If you or your collaborative meets with your legislator to talk about the potential impact of the bill, you are lobbying if you say, "Don't vote for the bill." You are not lobbying if you say, "We are concerned that this bill will make it easier for older adolescents to purchase alcohol, and national data show that nearly one-third of motor vehicle deaths of teens involved alcohol."
- You testify at a legislative committee, giving balanced information about both the positive and negative potential impact of the legislation.
- You meet with a non-legislative group, such as a school board, the state board of health, a chamber of commerce, a civic club, police chief, a trade association, etc.
- You host or attend appreciation luncheons, breakfasts, or legislative wrap-up sessions.
- You sponsor a candidates' forum, as long as you do not endorse a candidate or take a position on an issue to be voted on, such as a referendum or constitutional amendment.
- You inform legislators about the results of nonpartisan analysis, study or research.

You ARE lobbying if:

- You ask a legislator to vote for or against a particular bill.
- You ask others to contact their legislator and ask them to vote for or against legislation.
- You send a letter to legislators and ask them to veto a bill.

It is important to remember that legislators and policymakers appreciate and value non-biased information provided to them by state employees. Legislators and policymakers want to know what the potential impact of their decisions may be.

Appendix C

Access to Cancer Care Initiative Submissions from CCC Coalitions/Programs

Increasing Access to Cancer Care:
An Action Guide for Comprehensive Cancer Control Coalitions

**Access to Cancer Care Initiative Submissions from CCC
 Coalitions/Programs**

*Current contact information for these state and tribal CCC coalitions/programs can be found at: <http://cancercontrolplanet.cancer.gov/>

*Coalition/Program and Location	Project/Initiative Name	Access issue addressed/area of focus
California Dialogue on Cancer	Access to Cancer Care Community Projects	Pilot program gave small grants to 5 communities to implement access to cancer care strategies in the CA cancer plan ; CDOC provided training to the local agencies; additional grants planned for 2007/2008
Cherokee Nation Comprehensive Cancer Control Program	Cherokee Nation Colorectal Cancer Project	Increase colorectal cancer screening through Cherokee Nation Health Services; ongoing project includes identification of barriers to screening for men, development of culturally appropriate risk assessment tool and approach to raising awareness
Colorado Comprehensive Cancer Program/Colorado Cancer Coalition	Colorectal Cancer Screening Promotion in CO: Addressing a Public Health Issue with a Comprehensive Approach	Access to colorectal cancer screening services for underserved and underinsured in CO; patient navigation services to ensure compliance; treatment for those diagnosed; tobacco excise tax funding
Delaware Division of Public Health	Cancer Care Coordination Program	Patient navigation ; statewide-integrated hospital-based system that provides a care coordinator for every person diagnosed with cancer in Delaware; tobacco excise tax funding
Massachusetts Comprehensive Cancer Control Coalition	Primary Care Practice Quality Improvement Initiative to Increase Colorectal Cancer Screening	Remove systemic/structural barriers to colorectal cancer screening ; partnership with MassPro, the state quality improvement organization; physician advisors work with high and low tech practices to assess and develop sustainable systemic changes that will increase screening; part of an overall pay for quality performance demonstration project with CMS
Maine Comprehensive Cancer Control Program/Maine Cancer Consortium	Southern Maine Colon Screening Project	Pilot program to increase colorectal cancer screening by reducing financial barriers; provided FOBT kits via mail

*Coalition/Program and Location	Project/Initiative Name	Access issue addressed/area of focus
Kansas Comprehensive Cancer Control and Prevention Partnership	Survey of Cancer Centers	Improve patient navigation services; survey of 41 cancer centers statewide identified needs, gaps and barriers to accessing quality cancer services in the state
Michigan Cancer Consortium	Michigan Colorectal Cancer Awareness Network	Increase proportion of average-risk people who report having received appropriate screening and follow up of abnormal screening; supplies resource materials for public education activities and networking opportunities for participating organizations; example of consortium member taking ownership of cancer plan strategy
Michigan Cancer Consortium	Michigan Colorectal Cancer Screening Program	Improve access to colorectal cancer screening for underinsured and uninsured men and women; 15 county area; partially donated services and supplies ; enhanced partnerships at the community level
Michigan Cancer Consortium	Assessment of Michigan Hospital-Based Palliative Care Programs	Access to palliative care services; survey regarding location, availability and function of palliative care programs
Nebraska C.A.R.E.S. (CCC Coalition)	Cancer Center Networking	Increase access to appropriate and effective cancer treatment and care ; developing a network of cancer centers who work together on issues of mutual concern including community outreach, promotion of services and resources and referral of patients to cancer specialists; completed survey of cancer centers
Nebraska C.A.R.E.S. (CCC Coalition)	Clinical Trials Accrual	Increase accrual to cancer clinical trials ; part of networking cancer centers project (above); cancer centers sharing resources and information about availability of clinical trials
Nebraska C.A.R.E.S. (CCC Coalition)	CRC Supplement to Omaha World Herald	Increase colorectal cancer screening in greater Omaha metropolitan area; using media to increase awareness
Nebraska C.A.R.E.S. (CCC Coalition)	UNMC CARES Research Initiative	Identification of research and potential funding to address cancer disparities in NE; expanded to translating research into practice in the community
Nebraska C.A.R.E.S. (CCC Coalition)	Tobacco Control Policy	Access to tobacco cessation services; toolkit designed to address tobacco use of patients entering acute care hospitals; encouraging hospitals to adopt policy re: identifying tobacco users and offering tobacco cessation services

*Coalition/Program and Location	Project/Initiative Name	Access issue addressed/area of focus
Northern Plains Comprehensive Cancer Control Program (Tribal Program)	Cancer Education Summits, Seminars and Workshops	Increase general cancer awareness in tribal communities; regional cancer summits including Cancer 101 curriculum
Northern Plains Comprehensive Cancer Control Program (Tribal Program)	Increase Access to Quality Data	Address issue related to knowledge and awareness of cancer and the lack of cancer data for American Indians in the region; helping tribes understand how they can access and use data
Northern Plains Comprehensive Cancer Control Program (Tribal Program)	Cancer Caregiver Education Program	Increase resources, knowledge and skills of family/community caregivers ; culturally appropriate toolkit and workshops for native American family/community caregivers; train the trainer program for nurses and students to expand reach
Northern Plains Comprehensive Cancer Control Program (Tribal Program)	Native American Cancer Survivor Support Group	Provide cancer survivors with a place for social support, information, education and resources when needed
South Carolina Cancer Alliance	Advocacy for Change: Access to Prevention and Treatment Services	Advocacy and Policy Task Force instrumental in changes to SC Medicaid policy expanding services for breast and cervical cancer treatment and colorectal cancer screening
South Carolina Cancer Alliance	Family Access to Pediatric Cancer Resources in SC	Development of a Pediatric Cancer Family Resource Guide and dissemination strategies; result of participation in Lion in the House film broadcast/focus groups; partner with existing programs
South Dakota Comprehensive Cancer Control Coalition	Legislation simplifying Advance Directives	Successful legislative effort resulting in changes in requirements for authorizing medical procedures (advance directives) at the end of life, including close friends as well as family members; developed a brochure to explain changes
South Dakota Comprehensive Cancer Control Coalition	Special Edition of SD Journal of Medicine re: End of Life and Palliation	Educate providers and general public on end of life issues and promote programs focused on end of life care; partnership with Northern Plains CCC Program
South Dakota Comprehensive Cancer Control Coalition	Gas Cards for Travel to Breast Cancer Screening Sites	Access to screening services in rural area ; travel reimbursement ; partnership with Northern Plains CCC Program
South Dakota Comprehensive Cancer Control Coalition	Survivor Treatment Brochures	Improve access to quality care ; reduce financial and geographical barriers by providing information (brochure) about treatment resources available

*Coalition/Program and Location	Project/Initiative Name	Access issue addressed/area of focus
Washington Comprehensive Cancer Control Program	Increasing Colon Cancer Screening in WA	Increase colorectal cancer screening rates through increasing provider knowledge and skills, awareness in the workplace and employee screening rates at participating worksites by reducing barriers; provider counseling tools; worksite education; distribution and tracking of FOBT kits in worksites; RFP program to support community projects
Wisconsin Comprehensive Cancer Control Program	Milwaukee Regional Cancer Care Network	Assessment of access to cancer care in Milwaukee area; goal is to promote access to care and eliminate disparities in Milwaukee; pilot program; funding from UW-School of Medicine; evaluating partnership development through use of “synergy score”
Wyoming Comprehensive Cancer Control Consortium	Electronic Tumor Board Pilot Project	Increase access to quality care in WY through implementation of a statewide/regional/in-house tumor board system ; linking rural hospitals via videoconference and supporting regional and in-house oncology team communication/coordination
Wyoming Comprehensive Cancer Control Consortium	Wyoming Cancer Control Act/Access to Colorectal Cancer Screening	Consortium colorectal cancer task force successfully advocated for passage of 2007 WY Cancer Control Act which appropriated \$1.4 million for the creation of the WY colorectal cancer early detection program , providing colonoscopies to men and women at or below 250% of the federal poverty level; also created line item in the state general fund for cancer control initiatives that can be expanded and measured over time.



Collaborating to Conquer Cancer

1776 Eye Street, NW
9th Floor
Washington, DC 20006
800.830.1827
202.756.1600
202.756.1515 FAX
www.c-changetogether.org