Iowa Consortium For Comprehensive Cancer Control

Reducing the Burden of Cancer in Iowa: A Strategic Plan for 2006-2011

May 2006

Reducing the Burden of Cancer in Iowa: A Strategic Plan for 2006-2011 • May 2006

Iowa Department of Public Health
Promoting and protecting the health of Iowans

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Supported by the Grant/Cooperative Agreement Number U55/CCU721906-04 from the Centers for Disease Control and Prevention.
Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

ACKNOWLEDGEMENTS

Reducing the Burden of Cancer in Iowa: A Strategic Plan for 2006-2011 has been a collaborative effort by the organizations and individuals of the ***Iowa Consortium for Comprehensive Cancer Control*** (ICCCC). This statewide effort has drawn on the talents, time, expertise, resources and support of the members of the ***Consortium***. The revision of the plan was coordinated by the Executive Committee of the ICCCC and the staff of the Comprehensive Cancer Control (CCC) program at the Iowa Department of Public Health (IDPH).

Members of the Executive Committee, recognized here for their commitment to the project, include: Mary Ellen Carano, RN, MSW, William Bliss Cancer Center at Mary Greeley Medical Center; Vickie Evans, Wellmark Blue Cross Blue Shield of Iowa; Lori Hilgerson, MPH, CHES, Iowa Foundation for Medical Care; Kim Lansing, American Cancer Society, Midwest Division; Amber Leed Kelly, Alegent Health Immanuel Medical Center; Stephanie Loes, MS, Healthy Linn Care Network; Charles Lynch, MD, PhD, State Health Registry of Iowa, University of Iowa; Pat Ouverson, RN, American Cancer Society, Midwest Division; Ken Petersen, BS, American Cancer Society Volunteer; Kris Sargent, RN, OCN, Mercy Regional Cancer Center, Cedar Rapids; Sue Scoles, RN, BSN, William Bliss Cancer Center at Mary Greeley Medical Center; Michele West, PhD, State Health Registry of Iowa, University of Iowa; and Karla Wysocki, MA, CHES, American Cancer Society, Midwest Division. Special thanks to the Chair of the ICCCC, George Weiner, MD, University of Iowa Holden Comprehensive Cancer Center and the Vice-Chair of the ICCCC, Ron Nielsen, American Cancer Society Volunteer, for all of their hard work and dedication.

Special appreciation is given to the two coordinating agencies of the CCC initiative—the Iowa Department of Public Health and the American Cancer Society, Midwest Division. In particular, we would like to acknowledge the hard work of Jill Myers Geadelmann, BS, RN, Chief, Bureau of Chronic Disease Prevention & Management; Holly Smith, CCC Program Coordinator; Sarah Kitchell, Partnership Program Coordinator, National Cancer Institute – Cancer Information Service and the IDPH CCC program; and Jolene Carver, Program Consultant. Recognition is also given to the Centers for Disease Control and Prevention, specifically Lorrie Graaf, CDC Public Health Advisor, for her expertise and support.

The process of revising Iowa's Comprehensive Cancer Control plan has brought together many people and organizations to examine our progress in the fight against cancer—reminding us all that by working together, we will conquer cancer!

DEDICATION

The Iowa Comprehensive Cancer Control Plan is dedicated to the people of the state whose lives have been touched by cancer. They have reflected the face of cancer in Iowa, asked the question "why can't we do something more about cancer," and provided the impetus for a collaborative effort to reduce the burden of cancer in our state.

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IOWA CONSORTIUM FOR COMPREHENSIVE CANCER CONTROL

REDUCING THE BURDEN OF CANCER IN IOWA: A STRATEGIC PLAN FOR 2006-2011

EXECUTIVE SUMMARY

Cancer exacts a terrible toll on Iowa year after year. The Iowa Cancer Registry estimates that in 2006, over 16,000 Iowans will learn they have cancer and nearly 6,300 Iowans will die from the disease.[1] That's the bad news. The good news is that research advances mean that cancer is no longer the automatic death sentence it once was. More than half of the Iowans who have cancer will survive it, and each year the number of cancer survivors in Iowa grows.

Iowa has the opportunity to save even more of our fellow citizens from the consequences of cancer by using proven techniques for cancer prevention, early detection, and treatment. These approaches have been working—from 1993 to 2002, there was a 23 percent drop in the number of deaths from breast cancer and 21 percent drop in deaths from prostate cancer in the state.[2] Improvements in the quality of life for cancer survivors as well as active participation in the nation's cancer research enterprise will continue to advance progress.

With further coordination and continued work, Iowa can significantly change the course of cancer and save more lives. As organizations from the private, government, and not-for-profit sectors work together in a comprehensive, statewide approach to cancer control, fewer people will suffer under the burden of cancer.

The ***Iowa Consortium for Comprehensive Cancer Control*** was formed in 2001 to coordinate the efforts of those fighting cancer. The ***Consortium*** consists of more than 100 individuals representing 50 agencies and organizations across the state. A list of organizations and individuals involved in the ***Consortium*** can be found in Appendix B.

As its first step, the ***Consortium*** created this comprehensive, statewide cancer plan to address critical cancer problems in Iowa. They have set priorities for preventing, detecting and treating cancer, caring for cancer survivors, and encouraging clinical cancer research. Members from the ***Consortium*** have already begun implementation of the strategies listed in this plan.

The work of the ***Consortium*** has been supported by the Iowa Department of Public Health, which submitted a competitive application for funding to the U. S. Centers for Disease Control and Prevention (CDC). Initially, Iowa was awarded a grant to create this plan; currently, Iowa receives funding from the CDC to implement the strategies of the plan.

[1] Iowa Cancer Registry, State Health Registry of Iowa. *Cancer in Iowa: 2006*. www.public-health.uiowa.edu/shri/Pubs.html
[2] Iowa Cancer Registry, State Health Registry of Iowa. *Cancer in Iowa: 2004*. www.public-health.uiowa.edu/shri/Pubs.html

VISION

The *Iowa Consortium for Comprehensive Cancer Control*:
WORKING TOGETHER TO CONQUER CANCER.

GOALS

The goals for Iowa's Comprehensive Cancer Control Plan are:

- Whenever possible, prevent cancer from occurring.
- When cancer does occur, find it in its earliest stages.
- When cancer is found, treat it with the most appropriate therapy.
- Assure that the quality of life for every cancer survivor is the best it can be.
- Move research findings more quickly into prevention, treatment, and control practices.

If the citizens of Iowa work effectively and vigorously to address the goals outlined above, we can expect to see the following:

- Fewer cases of cancer.
- Fewer deaths from cancer.
- Increased survival from cancer.
- Improved quality of life for cancer patients and their loved ones.
- Long-term cost savings for cancer treatment and rehabilitation.
- More effective utilization of health care dollars and other resources.
- Fewer disparities in the cancer experience among Iowa's diverse populations.

The ***Consortium*** stands behind this plan and calls on Iowa's public officials, other decision-makers, and citizens to do likewise. More importantly, the ***Consortium*** encourages people and organizations from across the state to join them and become involved in its implementation.

There is no better time than now to confront cancer in Iowa and take full advantage of what is already known about prevention and treatment. There is no better way to do so than to work collectively across the state to make it happen. There is no one better to address Iowa's cancer problems than the people of Iowa themselves. This plan provides a framework for what needs to be done. Now Iowans must stand up and do it.

GUIDING PRINCIPLES

The following principles guide the development and implementation of the Iowa Comprehensive Cancer Control Plan. The plan and the work of the ***Consortium*** will:

1. Incorporate input from a wide spectrum of Iowans, including those most affected by cancer.

2. Address the cancer needs of all Iowans while addressing population disparities in the cancer experience.

3. Make specific recommendations that are results- and action-oriented.

4. When available, use data to make decisions regarding cancer prevention, early detection, treatment, quality of life, and research approaches and priorities.

5. Include mechanisms to assure accountability for implementing the recommendations.

6. Encourage Iowans from all walks of life and communities across the state to get involved in addressing the burden of cancer.

7. Call for all Iowans to have access to comprehensive cancer services and care.

8. Promote the efficient use of health care resources, especially those allocated for cancer.

9. Acknowledge the right of Iowans to make choices about cancer treatment and quality of life issues.

10. Build on the existing systems and resources within the state for cancer control.

INTRODUCTION: THE FACE OF CANCER IN IOWA

Cancer is the second leading cause of death in Iowa. According to the Iowa Cancer Registry, an estimated 16,000 Iowans will be diagnosed with cancer, and 6,300 will die from the disease in 2006. Annually, cancer accounts for about 230 of every 1,000 deaths in Iowa and affects Iowans in every county.[3] Special demographic and geographic factors mean that Iowa's cancer picture is unique.

Age & Cancer:

The National Cancer Institute reports that nearly 60 percent of new cancers occur in persons aged 65 and older. Of all cancer deaths, 70 percent occur in this group.[4]

This greatly affects Iowa. The 2000 US Census ranked Iowa second in the nation in the percentage of elderly over the age of 85 (2.2%) and fourth in percentage of the total population who are age 65 and older (14.9%).[5]

Race & Ethnicity & Cancer:

The U.S. Census estimates that only about 7 percent of Iowa's population is considered a racial or ethnic minority; however, this population often suffers under a disproportionate burden of cancer (see Disparities section). The small numbers of these populations, often clustered in metropolitan areas, make interpretation of data difficult.

Geographical Location & Cancer:

Iowa is largely a rural state, with about 52 persons per square mile.[6] Access to cancer care specialists, difficulties with transportation, and other issues associated with rural populations place additional burden on cancer patients and their families.

[3] Iowa Cancer Registry, State Health Registry of Iowa. *Cancer in Iowa: 2005*. www.public-health.uiowa.edu/shri/Pubs.html
[4] National Cancer Institute, SEER Program Data, 1994-1998. www.seer.cancer.gov
[5] Census 2000. http://factfinder.census.gov
[6] Census 2000. http://factfinder.census.gov

HEALTHY IOWANS 2010

The *Healthy Iowans 2010* report, written in the late 1990s, outlines goals for decreased mortality in the cancers listed below. The *Healthy Iowans 2010 Mid-Course Revision* illustrates that overall cancer mortality dropped 4 percent from 1994-1996 to 2000-2002.[7] The Iowa Cancer Registry estimates this decrease in mortality means that ***1,601 lives have been saved.***

The ***Consortium*** is responsible for several of the goals listed in the Cancer Chapter of the *Healthy Iowans 2010* report and has reported progress towards those goals in the *Healthy Iowans 2010 Mid-Course Revision*. The ***Consortium*** continues to support the cancer goals expressed in *Healthy Iowans 2010*. The strategies and priorities expressed in this plan are fully consistent with those goals. This plan also includes strategies with outcomes extending beyond the incidence and mortality goals of *Healthy Iowans 2010*.

MEASURED PROGRESS TOWARD CANCER MORTALITY GOALS FOR YEAR 2010, I0WA

GOAL	CANCER SITE	GENDER	1994-96 BASELINE RATE*	2000-02 RATE*	PERCENT IMPROVEMENT	ESTIMATED LIVES SAVED, 1997-02@
2-1	All Sites	M & F	196.4	188.5	4%	1,307
2-4	Lung	M & F	54.1	51.6	5%	420
2-5	Breast	F	29.0	24.1	17%	359
2-6	Cervix	F	2.6	2.3	12%	25
2-7	Colorectum	M & F	23.2	21.0	9%	292
2-8	Oral Cavity & Pharynx	M & F	2.6	2.2	15%	164
2-9	Prostate	M	36.0	29.3	19%	425
2-10	Skin Melanoma	M & F	2.5	2.2	12%	16

N=1,601

* Expressed per 100,000 and age-adjusted to Year 2000 U.S. Standard
@ Using indirect standardization with age-specific rates for 1994-96 as the standard
Note: Between 1994-96 and 1999-01, all sites cancer incidence has increased 1.4%.

Source: The Iowa Cancer Registry, State Health Registry of Iowa, April 2006

[7] *Healthy Iowans 2010 Mid-Course Revision*. July 2005. Iowa Department of Public Health. www.idph.state.ia.us/bhpl/healthy_iowans_2010.asp

THE CLIMATE FOR COMPREHENSIVE CANCER CONTROL

In 2001, the Iowa Legislature commissioned a report on the burden of cancer in the state. The Iowa Department of Public Health and the Comprehensive Cancer Control Study Committee worked throughout that year to produce a full report, *The Face of Cancer in Iowa*. From this report, the ***Consortium*** was formed.

The Face of Cancer in Iowa listed major assets and significant challenges in the fight against cancer, including:

Major Assets

- Iowa has a history of strong, cooperative, and successful public-private partnerships to address major issues the state faces.
- Iowa has a strong voluntary presence that is focused on cancer issues.
- Iowa has strong legislative interest and leadership on cancer.
- Iowa has a strong medical infrastructure devoted to cancer control, including a National Cancer Institute designated Comprehensive Cancer Center, university-based cancer training and research programs, and members of the Association of Community Cancer Centers found around the state.

Challenges

- The current economy of the state is weak. It is not one in which new programs are readily launched.
- Cancer detection tests are under-utilized.
- There are a large number of health and social issues competing for the attention of the public and policy makers.
- Iowans continue to use tobacco and are getting more obese.

PRIORITY STRATEGIES FOR IMPLEMENTATION

Iowa's cancer control plan is currently in active implementation. As part of a periodic assessment in October 2005, the ***Consortium*** met to discuss progress and evaluate priorities. The following four areas emerged as Iowa's top cancer priorities:

1. Tobacco Control

- **a.** Eliminate the public's exposure to secondhand smoke in workplaces, restaurants, and all other public facilities. *(Goal #1, Problem #1, Strategy D)*
- **b.** Increase the excise tax on cigarettes by $1.00, making the total tax per pack $1.36. *(Goal #1, Problem #1, Strategy A)*
- **c.** Increase funding for Iowa's tobacco prevention program to make it comprehensive in scope. *(Goal #1, Problem #1, Strategy E)*

2. Increase screening/early detection for all Iowans

- **a.** Enhance the ability of all health care providers to recommend or provide early detection services, programs, and procedures for their patients. *(Goal #2, Problem #2, Strategy A)*
- **b.** Increase general awareness of cancer screening guidelines among Iowans. Increase the general knowledge of Iowans regarding personal responsibility for adhering to cancer screening guidelines to detect cancers at earlier, more treatable stages. *(Goal #2, Problem #1, Strategy A)*
- **c.** Decrease the financial barriers that restrict Iowans' abilities to access early detection cancer screenings through increased public and provider knowledge of insurance plan coverage options and other non-traditional resources, including free services, for cancer early detection services. *(Goal #2, Problem #3, Strategy B)*
- **d.** Advocate increasing resources for early detection cancer screenings at entities that provide services at little or no cost to the service recipient. *(Goal #2, Problem #3, Strategy C)*
- **e.** Assess geographic distribution of health care providers trained to perform and interpret early detection screening services for cancer to identify utilization and access patterns that will ultimately increase the percentage of Iowans that receive screening according to the recommended screening guidelines. *(Goal #2, Problem #3, Strategy A)*

3. Access to treatment

- **a.** Identify gaps in treatment options and resources for underserved cancer patients. *(Goal #3, Problem #3, Strategy A)*
- **b.** Encourage insurance carriers to provide coverage through insurance plans for clinical cancer trial participation and cover costs of routine patient care when enrolled in a clinical cancer trial. *(Goal #5, Problem #1, Strategy A)*

4. Holistic view of cancer

- **a.** Increase awareness of quality of life issues and skills to effectively engage survivors in making decisions related to treatment and quality of life. *(Goal #4, Problem #1, Strategy A)*
- **b.** Increase the awareness of the relationship of obesity, physical activity and nutrition to cancer through public education. *(Goal #1, Problem #2, Strategy A)*
- **c.** Maintain and expand the ICCCC website as a resource accessible to both patients and healthcare providers and incorporate it into a broader communication/education source for cancer information and resources. *(Crosscutting Strategy)*

GOAL 1:
WHENEVER POSSIBLE, PREVENT CANCER FROM OCCURRING.

Doctors often cannot explain why one person develops cancer and another does not. But research shows that certain risk factors such as growing older, tobacco use, sunlight, environmental exposure, family history, alcohol use, poor diet, lack of physical activity, or being overweight increase the chance that a person will develop cancer. While some risk factors—like growing older or family history—cannot be avoided, many people can reduce their risk of cancer by staying away from risk factors whenever possible. According to the National Cancer Institute, scientists estimate that as many as 50 to 75 percent of cancer deaths in the United States are caused by preventable human behaviors such as smoking, physical inactivity, and poor dietary choices.[8]

Priority Strategies

Priority strategies as determined by the full ***Consortium*** for this goal are:

- Eliminate the public's exposure to secondhand smoke in workplaces, restaurants, and all other public facilities. *(Goal #1, Problem #1, Strategy D)*
- Increase the excise tax on cigarettes by $1.00, making the total tax per pack $1.36. *(Goal #1, Problem #1, Strategy A)*
- Increase funding for Iowa's tobacco prevention program to make it comprehensive in scope. *(Goal #1, Problem #1, Strategy E)*
- Increase the awareness of the relationship of obesity, physical activity and nutrition to cancer through public education. *(Goal #1, Problem #2, Strategy A)*

Cancer Problem #1

Each year, tobacco-related illnesses take the lives of 4,489 Iowans and consume $794 million in health expenditures.[9] In 2001, 1,734 Iowans died from cancers due to smoking and tobacco use. Although the rates of tobacco use among Iowans 18 years and older have declined over the past years, 20 percent of Iowans still smoke.[10] The use of tobacco among Iowa youth has significantly dropped (down 7% from 2002), but 7 percent of middle school students and 20 percent of high school students report using tobacco products.[11]

[8] Cancer Trends Progress Report: 2005 Update. http://progressreport.cancer.gov/doc.asp?pid=1&did=2005&mid=vcol&chid=21
[9] CDC Smoking Attributable Morbidity, Mortality, and Economic Calculations 1997-2001 www.cdc.gov/tobacco/sammec/
[10] 2004 Iowa Adult Tobacco Survey: www.idph.state.ia.us/tobacco/common/pdf/ATS_2004_Final_Draft.pdf
[11] 2004 Iowa Youth Tobacco Survey: www.idph.state.ia.us/tobacco/common/pdf/iyts_2004_highlights.pdf

STRATEGY A:

Increase the excise tax on cigarettes by $1.00, making the total tax per pack $1.36.

Rationale

According to the CDC, substantial scientific evidence shows that higher cigarette prices result in lower overall cigarette consumption. Most studies indicate that a 10 percent increase in price will reduce overall cigarette consumption by 3 to 5 percent. Youth, minorities, and low-income smokers are two to three times more likely to quit or smoke less than other smokers in response to price increases.[12]

At only $0.36 per package, Iowa's cigarette excise tax is well below the national average of $0.92 per pack, placing the state 42nd out of the 50 states. Of the surrounding states, only Missouri has a lower tax. Despite being the first state to impose a state tax on cigarettes in the country, Iowa has not increased its tax since 1991.[13]

If Iowa's excise tax is increased, it is estimated that $217 million in revenue will be generated the first year.

Outcomes

1. Decreased prevalence of youth and adult tobacco use.
2. Decreased state tax dollars spent on tobacco-related illnesses.
3. Decreased private funds (health insurance premiums) spent on tobacco-related illnesses.
4. Decreased incidence of tobacco-related cancers.
5. Decreased number of tobacco-related deaths.
6. Increased number of people who attempt to quit using tobacco.
7. Potential funding made available for use in improving the health of Iowans.

STRATEGY B:

Increase awareness of and participation in current programs for smoking and other tobacco product cessation.

Rationale

According to the CDC, the annual health care cost attributed to tobacco use in Iowa is $794 million. Of this amount, $277 million is paid for by the state's Medicaid Program.

Currently, there are more than 100 cessation programs targeting adults and over 40 programs targeting youth in Iowa. By removing barriers that impact access to cessation programs (e.g., inadequate funding, limited or no transportation, the need for child care, and lack of language-appropriate materials), services provided by these programs can be increased.

[12] www.cdc.gov/tobacco/sgr/sgr_2000/factsheets/factsheets_taxation.htm
[13] In 1921, Iowa became the first state to add a state cigarette tax onto the federal excise tax. Source: IDPH.

Outcomes

1. Increased number of calls to Iowa's Quit Line.
2. Increased number of Iowans who attempt to quit the use of tobacco products.
3. Decreased prevalence of tobacco use among youth and adults.

STRATEGY C:

Incorporate tobacco product cessation into counseling programs provided by licensed substance abuse treatment agencies.

Rationale

According to the National Institute on Alcohol Abuse and Alcoholism, extensive research supports the observation that "smokers drink and drinkers smoke." Moreover, the heaviest alcohol consumers are also the heaviest consumers of tobacco. Almost 85 percent of people who are in recovery from alcohol addiction are smokers, compared with 25 percent of the general public. Smokers in alcohol recovery may be more addicted to nicotine than other smokers. Because of the synergistic effect of alcohol and tobacco use, individuals with a history of heavy drinking and smoking are at increased risk for cancers of the head and neck.[14]

Outcomes

1. Decreased prevalence of tobacco use among those recovering from alcohol abuse.
2. Decreased cancer incidence among recovering alcoholics.
3. Decreased tobacco-related cancer deaths.

STRATEGY D:

Eliminate the public's exposure to secondhand smoke in workplaces, restaurants, and all other public facilities.

Rationale

Iowa's Clean Indoor Air Act states, "No person may smoke in a public place or at a public meeting except in designated smoking areas."[15] Although the law is designed to protect Iowans' health, comfort, and environment by restricting smoking to limited areas of public places, it does not require special barriers or ventilation to separate smoking and non-smoking areas.

Environmental tobacco smoke has been classified as a Group A carcinogen by the Environmental Protection Agency. This means it has been known to cause cancer in humans. Studies show a direct relationship between exposure to environmental tobacco smoke and adverse health effects in non-smokers and a firm causal relationship has been established between lung cancer and smoke that has been exhaled by smokers.

[14] National Institute on Alcohol Abuse and Alcoholism, http://pubs.niaaa.nih.gov/publications/aa39.htm
[15] www.idph.state.ia.us/tobacco/common/pdf/cleanair.pdf

Iowans are supportive of these efforts; according to the 2004 Iowa Adult Tobacco Survey, 91 percent of Iowans believe that breathing secondhand smoke is harmful, and 88 percent believe that people should be protected from secondhand smoke.[16]

Outcomes

1. Decreased exposure to and effects of secondhand smoke (incidence and death).
2. Improved health of workforce.
3. Decreased health care costs for businesses and taxpayers.
4. Improved quality of work and leisure environments.

STRATEGY E:

Increase funding for Iowa's tobacco prevention program to make it comprehensive in scope.

Rationale

CDC recommends that every state establish a nine-component tobacco control program to prevent youth from starting to use tobacco products, promote quitting among adults and young people, eliminate exposure to secondhand smoke, and identify and eliminate the disparities related to tobacco use.[17] To assure that such programs are comprehensive, sustainable, and accountable, CDC has also recommended specific funding ranges for every state. For Iowa, it is recommended that the level of annual funding range from a minimum of $19.3 million to a maximum of $48.7 million.[18] Iowa's current level of state funding for tobacco control is approximately $5 million.

Funding from an increase in Iowa's cigarette excise tax could be used to increase the current budget of the state's Tobacco Use Prevention and Control Program to the minimum level recommended by CDC. Approximately 6 percent of the estimated $217 million that would be raised during the first year the tax increase is in effect would be needed to make the program comprehensive.

Outcomes

1. Decreased initiation of tobacco use among Iowa youth.
2. Decreased prevalence of tobacco use among Iowa's youth and adults.
3. Decreased non-smokers' exposure to secondhand smoke.
4. Decreased prevalence of tobacco use among Iowa's diverse populations.

[16] 2004 Iowa Adult Tobacco Survey www.idph.state.ia.us/tobacco/common/pdf/ATS_2004_Final_Draft.pdf
[17] CDC Best Practices for Comprehensive Tobacco Control Programs, 1999, www.cdc.gov/tobacco/bestprac.htm
[18] www.cdc.gov/tobacco/statehi/html_2002/iowa.htm

Cancer Problem #2:

Obesity increases the risk of some cancers. Experts have determined that obesity is associated with cancers of the colon, breast (postmenopausal), lining of the uterus, kidney, and esophagus; and other studies report a link between obesity and cancers of the gallbladder, ovaries, and pancreas.[19] A report in the *New England Journal of Medicine* estimated that in the U.S., 14 percent of cancer deaths in men and 20 percent in women were due to overweight and obesity.[20]

Obesity remains a significant problem in Iowa. Data from the 2005 BRFSS shows that 25.4 percent of Iowans are obese and an additional 37.1 percent of Iowans are overweight.[21] While this figure has been steady over the last few years, the fact remains that almost two-thirds of all Iowans are overweight or obese.

STRATEGY A:

Increase the awareness of the relationship of obesity, physical activity and nutrition to cancer through public education.

Rationale

The American Institute for Cancer Research (AICR) estimates between 30 and 40 percent of all cases of cancer are preventable by feasible and appropriate diets and by physical activity and maintenance of appropriate body weight.[22] However, a 2002 nationwide survey by AICR found that only 6 percent of those questioned could identify a link between these factors and cancer.[23]

Outcomes

1. Increased awareness stimulates behavioral change to reduce risk for cancers associated with obesity, nutrition, and physical activity.
2. Decreased prevalence of overweight/obese Iowans.
3. Decreased prevalence of cancers associated with these factors.

STRATEGY B:

Support the efforts of *Iowans Fit for Life*, a CDC-sponsored program charged with the creation of a comprehensive state plan to address physical activity and nutrition to prevent obesity and other chronic diseases.[24]

[19] National Cancer Institute Fact Sheet, Obesity & Cancer: www.cancer.gov/cancertopics/factsheet/Risk/obesity
[20] Calle EE, et al. (2003). Overweight, obesity, and mortality from cancer in a prospectively studied cohort of U.S. adults. *New England Journal of Medicine*. 348(17), 1625–1638.
[21] http://apps.nccd.cdc.gov/brfss/page.asp?yr=2005&state=IA&cat=DE#DE
[22] American Institute for Cancer Research/World Cancer Research Fund. (1997). Food, nutrition, and the prevention of cancer: a global perspective. www.aicr.org/research/report_summary.lasso#parttwo
[23] www.aicr.org/press/pubsearchdetail.lasso?index=1476
[24] For more information, visit: www.state.ia.us/iowansfitforlife/

Rationale

Partnering with *Iowans Fit for Life* will increase coordination and reduce duplication of chronic disease control efforts.

Outcomes

1. Increased coordination of projects and messages among public health initiatives and comprehensive state plans will maximize existing resources and expertise.
2. Increased awareness of the link between physical activity, nutrition and cancer.
3. Decreased prevalence of overweight/obesity among Iowans.
4. Decreased mortality associated with cancers linked to obesity.

STRATEGY C:

Support *Lighten Up Iowa*, a statewide campaign to reduce the prevalence of overweight and obesity among Iowans by increasing physical activity and improving food choices.[25]

Rationale

*Lighten Up Iow*a is an initiative supported by the IDPH, Iowa Games, and Iowa State University Extension that uses friendly team competition to promote physical activity and improved dietary habits. An evaluation of the program showed participant weight loss as well as sustained behavioral changes such as healthy eating and increased activity.[26]

Outcomes

1. Increased support for and utilization of *Lighten Up Iowa*.
2. Improved physical activity levels and healthy eating habits among participants.
3. Decreased prevalence of overweight/obesity among Iowans.
4. Decreased incidence of and mortality associated with cancers linked to obesity.

Cancer Problem #3

2004 BRFSS data show that 40 percent of adult Iowans reported experiencing sunburns, with 60 percent of the respondents, ages 18-24 years, indicating they had a sunburn in the past 12 months. Seasonal employees who work outdoors and ordinarily have limited exposure to the sun, are at higher risk for sunburn and skin damage. Children in the state are unnecessarily exposed to harmful effects of the sun at swimming pools, schools, and other public areas. Tan skin continues to be falsely synonymous with health and vitality. As a result, artificial means, such as tanning beds, are used to facilitate the belief that tan skin is a desirable "look," especially for youth.

[25] For more information, visit: www.lightenupiowa.org/
[26] Program evaluation can be found on this website: www.joe.org/joe/2005april/a6.shtml

STRATEGY A:

Develop an occupational safety plan that identifies skin protection strategies for seasonal, outdoor workers.

Rationale

Exposure to ultraviolet (UV) radiation is a significant risk factor for malignant melanoma, one of the most aggressive and deadly forms of skin cancer. Although the rate of new cases is low in Iowa, the death rate for skin melanoma is relatively high.[27] Death rates for melanoma are approximately twice as high in Caucasian males as Caucasian females. Iowans who are seasonal, outdoor workers usually do not maintain a base tan and, therefore, are at increased risk for sunburn, a primary risk factor for skin melanoma.

Outcomes

1. Unprotected sun exposure is identified as a priority health concern and is addressed as an occupational safety issue by Iowa's employers.
2. Increased use of sun protection methods among Iowans.
3. Decreased prevalence of sunburns.

STRATEGY B:

Implement community-based interventions, focusing on children and adolescents that: 1) increase awareness that sunburn is a risk factor for skin cancer, and 2) implement policy changes to help reduce overexposure to the sun.

Rationale

According to the Department of Dermatology at the University of Iowa, children receive about 80 percent of their lifetime sun exposure by the age of 18.[28] Protection from ultraviolet exposure during childhood and adolescence reduces the risk for skin cancer in adults. Schools and other community facilities such as swimming pools, playgrounds, and outdoor recreational centers need to be sun-safe spaces to reduce children's exposure to UV radiation.

Outcomes

1. Decreased prevalence of sunburns.
2. Decreased incidence of skin melanoma cancers.
3. Decreased number of deaths from melanomas.

[27] http://statecancerprofiles.cancer.gov/cgi-bin/quickprofiles/profile.pl?19&053
[28] http://tray.dermatology.uiowa.edu/SafeSun/SafeSun-2.html

STRATEGY C:

Implement a social marketing campaign to educate Iowa youth regarding the risks associated with excessive exposure to ultraviolet rays from artificial tanning devices.[29]

Rationale

Long-term exposure to artificial sources of ultraviolet rays like tanning beds increases both men's and women's risk of developing skin cancer. Additionally, women who use tanning beds more than once a month are 55 percent more likely to develop malignant melanoma, the most deadly form of skin cancer.[30] Therefore, persons who choose to use tanning devices should be aware of the potential risks and should follow the manufacturer's directions to minimize these risks.

Although there are approximately 1,400 registered tanning facilities in Iowa, no data regarding the incidence of burns is collected by local health departments during annual inspections.[31] Tanning facilities are required to report burns necessitating physician treatment to the Iowa Department of Public Health. However, the client must first report the burn to the facility.

Anecdotal information indicates that high school age females tend to use tanning facilities for special occasions such as prom or spring break and may experience burns while trying to achieve a tan too quickly. In Iowa, there are no legal age restrictions or parental consent requirements concerning the use of indoor tanning facilities.

Outcomes

1. Decreased incidence of skin burns related to use of tanning devices.
2. Establishment of a system to collect baseline data and track trends.
3. Development and implementation of data-driven interventions.

[29] Walsh, Diana Chapman, Rima E. Rudd, Barbara A. Moeykens, and Thomas W. Moloney (1993). "Social Marketing for Public Health," *Health Affairs*, (Summer) 104-19.
[30] According to the National Cancer Institute.
[31] Bureau of Radiological Health, IDPH

Cancer Problem #4:

According to the EPA, exposure to radon decay products (radon) is the second leading cause of lung cancer in the United States today and is responsible for about 21,000 lung cancer deaths in the U.S. annually.[32] Either smoking or radon exposure can independently increase the risk of lung cancer; however, exposure to both greatly compounds that risk.

Iowa leads the nation in the number of homes that test above the Environmental Protection Agency (EPA) recommended action level of 4.0 picocuries per liter (pCi/L). Collaborative IDPH and EPA surveys have demonstrated that 72 percent (or five out of seven) of Iowa homes contain radon levels above the recommended action level in the basement.

STRATEGY A:

Encourage homeowners and buyers to hire certified radon measurement specialists to test all buildings for radon before they are sold and at the time of sale.

Rationale

Radon is designated as a Class A carcinogen by the Environmental Protection Agency (EPA). According to the National Council on Radiation Protection, exposure to radon accounts for 55 percent of the average Americans yearly radiation dose. In Iowa, the radiation dose to the average individual from radon and its decay products is even higher. A large-scale epidemiology study performed in Iowa by researchers in the College of Public Health at the University of Iowa showed that people with an average radon exposure of 4 picocuries per liter (pCi/L) for 15 years had a 50 percent increase in the risk of developing cancer. [33]

Currently, no formal radon testing law exists that requires radon testing to be conducted when homes are sold in Iowa. Since Iowa has the highest percentage of homes above the EPA action level in the U.S., an Iowa law should be passed that requires radon testing by a certified radon measurement specialist of all homes during or prior to their sale in Iowa. Real estate professionals will need to comply and should be required to receive education concerning the health risk from the public's exposure to radon.

Outcomes

1. Increased public awareness of the link between radon exposure and lung cancer.
2. Increased number of dwellings tested for radon.
3. Decreased incidence of cancer related to radon exposure.
4. Decreased cancer deaths related to radon.

[32] www.epa.gov/radon/
[33] www.cheec.uiowa.edu/misc/radon.html

STRATEGY B:

Support the programs and activities of the Iowa Air Coalition and IDPH that promote radon mitigation in homes that have tested equal to or above four pCi/L.

Rationale

According to the EPA, radon accounts for more annual cancer deaths than pesticide applications, hazardous waste sites, toxic outdoor pollutants, and residual pesticides on food combined. High radon levels have been found in new and old homes, well-sealed and drafty homes, and homes with or without basements. Radon enters by infiltration through cracks and openings, seepage through pores in concrete, or through release of radon gas from waterborne radon sources such as wells. The EPA recommends that action be taken to reduce indoor radon levels if the radon concentration in the home on an annual basis is four pCi/L or higher.

Outcomes

1. Increased number of dwellings tested for radon.
2. Decreased incidence of cancer related to radon exposure.
3. Decreased cancer deaths related to radon.

STRATEGY C:

Encourage newly constructed homes and buildings to be built according to Appendix F: Radon Control Methods in the 2000 International Residential Building Code.

See http://www.bookmarki.com/2000-International-Residential-Code-p/1892395177.htm for Appendix listings.

Rationale

The 2000 International Building Code describes the installation of a passive radon system and describes what Radon Resistant New Construction (RRNC) features must be installed during construction. Produced by a partnership between International Code Council and Underwriters Laboratories, Inc. (UL), the code contains more than 25 UL Standards for Safety.

Currently, only a few Iowa cities require that RRNC features be installed in newly constructed residential structures. No formal reporting system exists to assess the number of RRNC systems installed on a regular basis.

Outcomes

1. Increased number of dwellings tested for radon.
2. Decreased incidence of cancer related to radon exposure.
3. Decreased cancer deaths related to radon.

Cancer Problem #5:

According to the National Cancer Institute, drinking alcohol increases the risk of cancers of the mouth, esophagus, pharynx, larynx, and liver in men and women, and of breast cancer in women. In general, these risks increase after about one daily drink for women and two daily drinks for men.

According to the National Institute on Alcohol Abuse and Alcoholism (NIAAA) 2 to 4 percent of all cancer cases are thought to be caused either directly or indirectly by alcohol. The strongest link between alcohol and cancer involves those of the upper digestive tract. An estimated 75 percent of esophageal cancers in the United States are attributed to chronic, excessive alcohol consumption, and nearly 50 percent of cancers of the mouth, pharynx, and larynx are associated with heavy drinking.

Alcohol is the most commonly used substance among adult Iowans and the substance that results in the most admissions to treatment services. Data from the 2005 BRFSS indicate that 18.6 percent of Iowans consumed five or more drinks on one occasion in the last 30 days.[34] This percentage is above the national median of 14.4 percent.

STRATEGY A:

Support the goals of the Governor's Office of Drug Control Policy's Drug Control Strategy.[35]

Rationale

The Governor's Office of Drug Control Policy's *Drug Control Strategy* serves as a guide for prevention services for alcohol, tobacco, and other drug abuse and related problems. The plan identifies standard goals to be addressed by state and local substance abuse comprehensive contractors/projects. Many of the goals focus on collaboration as a means of enhancing and strengthening interventions and thus making prevention services more effective.

Outcomes

1. Strengthened collaborative efforts for state substance abuse prevention.
2. Decreased incidence of cancers related to alcohol consumption.
3. Decreased cancer deaths that are alcohol-related.

[34] http://apps.nccd.cdc.gov/brfss/display.asp?cat=AC&yr=2005&qkey=7306&state=IA
[35] View the plan at: www.state.ia.us/government/odcp/docs/Strategy_06.pdf

Cancer Problem #6:

According to the National Cancer Institute, approximately 5 to 10 percent of all cases of cancer are hereditary. This means that a gene predisposing to the development of cancer (a mutation) is passed on from one generation to the next. While a mutated gene does not cause cancer, it can increase an individual's risk for cancer.

For example, women who carry a defective BRCA1 gene, which is critical for repairing mutated DNA, have as much as an 85 percent risk of developing breast cancer and a 65 percent risk for ovarian cancer. They also have an increased risk of developing secondary cancers after they get breast or ovarian cancer and generally develop cancer at an earlier age than non-carriers do.

An accurate gene test can tell if an individual has a disease-related mutation. Researchers have identified genes that carry increased susceptibility for breast, ovarian, colon, and some rare cancers.[36] Genetic testing for these mutations could help detect cancer in high-risk individuals at an early stage, leading to appropriate therapy; however, there are limitations and consequences to this testing that are best handled with the help of a counselor.

STRATEGY A:

Increase availability and knowledge of personalized cancer risk assessment and appropriate susceptibility/DNA testing.

Rationale

Personalized risk assessments are used to determine an individual's chance of developing cancer based on family history, environmental exposures, and lifestyle choices.

Individuals who are at high risk of developing cancer due to an inherited predisposition can benefit from DNA testing, careful counseling, and early and frequent surveillance to detect cancer in early stages. If susceptibility/DNA testing demonstrates an individual is not at increased risk despite a strong family history, anxiety for that individual can be reduced, and extraordinary screening and invasive prevention measures would not be necessary.

Outcomes

1. Increased number of qualified professionals in Iowa who offer cancer risk assessments.
2. Better use of information from susceptibility/DNA testing in medical management decision-making.
3. Decreased incidence of and mortality from hereditary cancers as a result of increased surveillance and preventive measures.

[36] "Understanding Gene Testing" DHHS and www.accessexcellence.org/AE/AEPC/NIH/index.html

GOAL 2:
WHEN CANCER DOES OCCUR, FIND IT IN ITS EARLIEST STAGES.

Cancer can be detected at earlier, more treatable stages. Early detection through cancer screening diminishes suffering for patients and their families, improves survival rates, and decreases the number of deaths due to cancer. Estimates of the premature deaths that could have been avoided through screening vary from 3 to 35 percent, depending on a variety of assumptions.[37]

Priority Strategies

Priority strategies as determined by the full ***Consortium*** for this goal are:

- Enhance the ability of all health care providers to recommend or provide early detection services, programs, and procedures for their patients. *(Goal #2, Cancer Problem #2, Strategy A)*
- Increase general awareness of cancer screening guidelines among Iowans. Increase the general knowledge of Iowans regarding personal responsibility for adhering to cancer screening guidelines to detect cancers at earlier, more treatable stages. *(Goal #2, Problem #1, Strategy A)*
- Decrease the financial barriers that restrict Iowans' abilities to access early detection cancer screenings through increased public and provider knowledge of insurance plan coverage options and other non-traditional resources, including free services, for cancer early detection services. *(Goal #2, Problem #3, Strategy B)*
- Advocate increasing resources for early detection cancer screenings at entities that provide services at little or no cost to the service recipient. *(Goal #2, Problem #3, Strategy C)*
- Assess geographic distribution of health care providers trained to perform and interpret early detection screening services for cancer to identify utilization and access patterns that will ultimately increase the percentage of Iowans that receive screening according to the recommended screening guidelines. *(Goal #2, Problem #3, Strategy A)*

[37] www.cancer.gov/cancertopics/pdq/screening/overview/healthprofessional

Cancer Problem #1:

Although screening use for most groups has increased over the years, overall rates are not optimal and major disparities remain.[38] According to the American Cancer Society (ACS), a significant proportion of the adult population does not receive regular screening, does not receive all recommended tests, or does not receive screening at all.[39]

This is true for Iowa. Although gains have been made in screening rates for cervical and breast cancers, screening rates for colorectal and other cancers remain low.[40] According to the 2004 BRFSS, only 31.7 percent of Iowans 50 years and older had a recommended blood stool test to screen for colon cancer in the past two years, and only 44.1 percent had a recommended endoscopy in the past five years. These low screening rates translate to late stage diagnosis of colorectal cancer and lower survival rates, with only 39 percent of colorectal cancers diagnosed at the earliest, most treatable stage.[41]

STRATEGY A:

Increase general awareness of cancer screening guidelines among Iowans. Increase the knowledge of Iowans regarding personal responsibility for adhering to cancer screening guidelines to detect cancers at earlier, more treatable stages.

Rationale

Several studies have identified lack of awareness as a barrier to screening.[42] Confusion about risk factors, frequency of screening tests, appropriateness of tests, and age at which to start are the main reasons cited. For example, in a study by Shelly Campo of the University of Iowa College of Public Health, residents from two rural counties in Iowa showed a lack of understanding of the risks for colorectal cancer and the recommendations for screening.[43]

Outcomes

1. Increased understanding of cancer screening guidelines in target population.
2. Increased consumer demand for early detection screenings.
3. Increased number of screenings or procedures performed, consistent with established cancer screening guidelines.
4. Decreased prevalence of cancer detected at later stages. (Initially, incidence will increase, but then will decline with continued, regular screenings by consumers.)

[38] Swan J, et al. (2003). Progress in cancer screening practices in the United States: results from the 2000 National Health Interview Survey. *Cancer*. 97(6) 1528-1540.
[39] Smith, Robert A. et al. (2005) American Cancer Society Guidelines for the Early Detection of Cancer, 2005. *CA Cancer J Clin* 55:31-44.
[40] www.idph.state.ia.us/brfss/common/pdf/2004BRFSSannual.pdf
[41] www.idph.state.ia.us/bhpl/common/pdf/healthy_iowans_2010_chapters/Healthy_Iowans_2010_Complete.pdf
[42] Achat, Helen et al. (2005) Who has regular mammograms? Effects of knowledge, beliefs, socioeconomic status, and health-related factors. *Preventative Medicine* 41, 312-320, and Klabunde, Carrie et al. 2005. Barriers to Colorectal Screening: A comparison of reports from Primary care physicians and Average-risk adults. *Medical Care* 43 (9), 939-944.
[43] Campo, Shelly et al. Perceptions of Colorectal Screening: Preliminary survey results for screened and unscreened rural Iowans. Report to the Iowa Department of Public Health. University of Iowa. June 2005

STRATEGY B:

Utilize the media to increase public awareness and understanding of early detection screening guidelines and practices to facilitate accurate information being reported to the public.

Rationale

Due to its wide reach, mass media can encourage increased use of health services such as cancer screening.[44] However, the Guide to Community Preventive Services reports that there is insufficient evidence to support interventions based on media coverage alone and that interventions to increase screening must address other issues such as barriers to access.[45]

Outcomes

1. Work to ensure effectiveness in reporting information about cancer as a major health issue by journalists.
2. Increased number of age-appropriate, early detection screenings performed.
3. Decreased prevalence of cancers detected at later stages. (Initially, incidence will increase, but then decline with continued, regular screenings by consumers.)
4. Increased number of consultations with local health professionals for expertise regarding screening guidelines.
5. Increased consumer demand for services.
6. Decreased confusion among physicians and the public regarding current, recommended screening guidelines.
7. Increased knowledge of media, health professionals and the public regarding where to obtain credible screening guideline resources.

[44] Grilli R, Ramsay C, Minozzi S. Mass media interventions: effects on health services utilisation. *The Cochrane Database of Systematic Reviews* 2002, Issue 1.
[45] www.thecommunityguide.org/cancer/screening/default.htm

Cancer Problem #2:

According to the American Cancer Society, the most important motivator for undergoing screening is a recommendation by a health care provider. Unfortunately, many Iowans report that their health care provider does not communicate the necessity of these recommended tests. According to the 2004 BRFSS, only 53 percent of Iowans 50 years and older reported that their physician recommended a screening test for colorectal cancer.[46] Consequently, when a provider did recommend screening, 76 percent of Iowans followed through.

According to the *Journal of the American Medical Association*, there are several factors that may affect physician adherence to guidelines, including a lack of awareness or familiarity with the guidelines, or a lack of resources, time, and/or referral sources.[47]

STRATEGY A:

Enhance the ability of health care providers to recommend or provide early detection services, programs, and procedures for their patients.

Rationale

According to the American Cancer Society, studies have consistently shown that the most important factor in whether or not an individual has ever had a screening test, or has been recently screened, is a recommendation from his or her health care provider. Yet, health care providers are typically limited in the amount of time actually spent with each patient. Tools for monitoring an individual patient's screening history will make it easier for health care providers to recommend appropriate cancer screening tests and procedures for each patient. A study by the American College of Physicians supports this strategy, showing that rates of cancer screenings are most likely to improve when health care providers make organizational changes such as changes in clinical procedures, staffing, and/or infrastructure.[48]

Outcomes

1. Increased number of screenings or procedures performed, consistent with established cancer screening guidelines.
2. Decreased prevalence of cancers detected at later stages. (Initially, incidence will increase, but then decline with continued, regular screenings by consumers.)
3. Decreased cancer mortality rates.

[46] www.idph.state.ia.us/brfss/common/pdf/2004BRFSSannual.pdf
[47] Cabana, Michael et al. (Oct 20, 1999). Why Don't Physicians Follow clinical practice guidelines? *JAMA*, 282(15).
[48] Stone, Erin et al. (2002) Interventions that Increase use of adult immunization and cancer screening services: a meta-analysis. *Ann Intern Med*. 136:641-651.

STRATEGY B:

Increase primary care provider knowledge and utilization of existing resources for non-traditional, publicly and privately funded payment for early detection cancer screening services.

Rationale

Providers may be reluctant to refer patients for testing when they feel there is no ability to pay for those services and for follow-up needs. Increasing their awareness of the existence of such services can reduce that reluctance and ultimately increase their utilization by patients.

Outcomes

1. Increased enrollment in publicly funded screening programs.
2. Increased number of screenings or procedures performed, consistent with established cancer screening guidelines.
3. Decreased prevalence of cancers detected at later stages. (Initially, incidence will increase, but then decline with continued, regular screenings by consumers.)
4. Decreased cancer mortality rates.

Cancer Problem #3:

Financial and cultural barriers as well as personal barriers, such as fear and embarrassment, may hinder Iowans from obtaining early detection screenings according to recommended guidelines. Many Iowans may have also been unable to receive screening services according to recommended guidelines due to the geographic distribution of health care providers trained to perform and interpret early detection screening services (i.e. colonoscopy, Pap tests, and mammography).

STRATEGY A:

Assess geographic distribution of health care providers trained to perform and interpret early detection screening services for cancer in order to identify utilization and access patterns that will ultimately increase the percentage of Iowans that receive screening according to the recommended screening guidelines.

Rationale

The capacity for early detection cancer screenings in Iowa (availability of health care providers who perform early detection screening) has not been sufficiently described.

Outcome

1. Areas in need of additional health care providers to perform cancer screenings will be identified.

STRATEGY B:

Decrease the financial barriers that restrict Iowans' abilities to access early detection cancer screenings through increased public and provider knowledge of insurance plan coverage options and other non-traditional resources, including free services.

Rationale

There is a lack of knowledge among Iowans who are insured regarding early detection cancer screening coverage through their insurance plans. Insured Iowans may be more likely to obtain early detection screening services if they know what cancer screening services their policy covers. For Iowans who are uninsured, there is a lack of knowledge about public and private foundation resources for early detection cancer screening. Uninsured Iowans may be more likely to access early detection cancer screening services if they know where to obtain them free or at reduced-cost.

Outcomes

1. Increased consumer demand for early detection cancer screenings.
2. Increased number of screenings or procedures performed, consistent with established cancer screening guidelines.
3. Increased number of Iowans seeking services through publicly or privately funded sources.
4. Decreased number of Iowans citing lack of insurance as a barrier to receiving routine cancer screenings.

STRATEGY C:

Advocate increasing resources for early detection cancer screenings at entities that provide services at little or no cost to the service recipient.

Rationale

Publicly funded entities that provide early detection cancer services may already be at capacity for serving low-income, underinsured, and uninsured populations. Additional resources will be required to meet the needs of underserved Iowans who seek cancer screening services.

Efforts to educate Iowans on the importance and benefits of detecting cancer at its earliest stages will motivate more Iowans of all economic levels to seek early detection cancer services.

Outcomes

1. Increased number of outreach efforts to encourage low-income Iowans to obtain screening services.
2. Increased number of low-income Iowans who receive early detection cancer screening services.
3. Increased enrollment in publicly funded screening programs.
4. Increased number of screenings or procedures performed, consistent with established cancer screening guidelines.
5. Decreased prevalence of cancers detected at later stages. (Initially, incidence will increase, but then decline with continued, regular screenings by consumers.)
6. Decreased cancer mortality rates.

STRATEGY D:

Decrease the screening-related barriers of personal fear and embarrassment that Iowans perceive and that inhibit access to routine early detection cancer screening services.

Rationale

Many barriers to cancer screening have been documented through scientific studies. Some of these vary by cancer types, the nature of the tests themselves, and across cultural groups. Fear and embarrassment are among those noted for certain cancers and cancer screening tests (e.g., colorectal cancer tests are viewed by some with more fear and embarrassment than screening tests for other cancers).

Outcomes

1. Decreased number of Iowans citing fear and embarrassment as barriers to receiving routine screenings.
2. Increased number of screenings or procedures performed, consistent with established cancer screening guidelines.
3. Decreased prevalence of cancers detected at later stages. (Initially, incidence will increase but then decline with continued, regular screening by consumers.)

STRATEGY E:

Decrease language and cultural belief-related barriers that prevent individuals from accessing early detection screening services. This can be accomplished by increasing the ability of health care providers to deliver care that is sensitive to various belief systems and that is understood in the many languages spoken by the increasingly diverse Iowa population.

Rationale

Iowa is made up of diverse population groups with unique experiences regarding cancer, how it affects them, and their approach to addressing it. These groups include, but are not limited to, people living in urban or rural areas, ethnic and racial minorities, and people of different socio-economic status. Issues of language and cultural barriers exist in Iowa that inhibit some Iowans from seeking early cancer detection and screening services. Because Iowa is becoming increasingly diverse, health care providers need to be able to communicate with non-English speakers and confront emerging cultural issues. Language barriers continue to exist, but there are educational resources available to increase cultural competency and inform health care providers about cultural barriers (e.g., the National Asian Women's Health Organization's resource guide for cultural barriers).

Outcomes

1. Decreased number of Iowans citing language differences and lack of cultural sensitivity as barriers to receiving routine early detection cancer screening services.
2. Decreased disparity with access to early detection cancer screening services among diverse and non-English speaking Iowa populations.
3. Decreased number of individuals who cite lack of health care provider cultural sensitivity as a barrier to obtaining early detection cancer screening.
4. Increased number of Iowans from various cultures and language groups who receive screenings consistent with established cancer screening guidelines.

GOAL 3:
WHEN CANCER IS FOUND, TREAT IT WITH THE MOST APPROPRIATE THERAPY.

Thanks to the advances of science, cancer treatments are advancing rapidly with more and more people surviving the disease. Unfortunately, not everyone has equal access to these lifesaving treatments. Barriers to accessing the most appropriate treatment can include a lack of adequate finances or insurance, a lack of transportation, and a lack of information on the part of patients and providers, as well as other cultural and language barriers.

Priority Strategies

Priority strategies as determined by the full ***Consortium*** for this goal are:

- Identify gaps in treatment options and resources for underserved cancer patients. *(Goal #3, Problem #3, Strategy A)*
- Maintain and expand the ICCCC website as a resource accessible to both patients and health care providers and incorporate it into a broader communication/education source for cancer information and resources. *(Crosscutting strategy)*

Cancer Problem #1:

Patient Education—Patients may lack adequate knowledge to understand their cancer disease process, treatment options, and treatment costs. Areas in which patients may be educated include how to effectively communicate with their physicians, the availability of clinical trials, the advantages and disadvantages of complementary and alternative therapies, and the need for compliance with treatment instructions.

STRATEGY A:

Utilize cancer support groups, health maintenance organizations (HMOs), insurance carriers, the American Cancer Society, the ***Consortium*** website, and other organizations for exchanging information among cancer patients, families/caregivers, survivors, and physicians.

Rationale

Educating and empowering patients about their disease process and treatment will lead to better cancer outcomes.

Outcomes

1. Patients will be better educated and more knowledgeable regarding issues related to their disease.
2. Improved patient satisfaction with cancer care and treatment outcomes.
3. Improved quality of life for cancer patients.
4. Improved compliance with cancer treatment regimen.
5. Increased number of cancer patients enrolling in clinical trials.
6. Cancer patients will be empowered to communicate effectively so their needs are met and interaction with physicians and patients will be improved.

Cancer Problem #2:

Physician Education — Some physicians and other health care professionals may be unaware of specific issues unique to the best care of the cancer patient. These issues include interaction and cooperation among different specialties (e.g., internists and oncologists), appropriate and timely use of sub-specialty referrals so that there is participation in current clinical trials, complementary and alternative therapies, and access to patient assistance programs.

STRATEGY A:

Develop a Speaker's Bureau and database of other resources to facilitate statewide networking and communication among physicians, such as primary care physicians and other primary care providers who diagnose cancer and oncologists who treat cancer.

Rationale

Physicians who provide care to cancer patients may not be communicating optimally with each other.

Outcomes

1. Enhanced networking and communication among specialty groups.
2. Improved treatment outcomes.
3. Improved quality of life and survival rates of cancer patients.

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.

STRATEGY A:

Identify gaps in treatment options and resources for underserved cancer patients.

Rationale

The assets and needs must be identified prior to implementation of other strategies.

Outcomes

1. Provide a baseline for many other strategies in this document.
2. Data on community resources, including clinical trials and support services, will be available for analysis.
3. Identify focal points for our efforts in communication, financial, and transportation interventions.
4. Resources can be brought to the most appropriate places, based on the data, which will increase patient access.
5. Interventions that are data-driven can be tracked in the future.

STRATEGY B:

Maintain and expand the ICCCC website as a resource accessible to both patients and health care providers and incorporate it into a broader communication/education source for cancer information and resources.

Rationale

It is confusing to search out cancer-related information on the Internet, which may include locating clinical trials and the contact information for sub-specialists across Iowa.

Outcomes

1. Increased patient and provider awareness of options available in Iowa and knowledge on how to obtain the information.
2. Increased annual participation in clinical trials.
3. Patients will have increased knowledge with which to choose and access health care providers.

STRATEGY C:

Coordinate with existing agencies to provide transportation for cancer patients to/from cancer treatment facilities (e.g., the American Cancer Society and the Area Agency on Aging).

Rationale

In a rural state such as Iowa, the ability to access adequate transportation services to and from treatments and medical appointments is a barrier to obtaining adequate treatment. Transportation services are often unavailable due to a lack of social support, differences in cultural norms, and geographic and financial barriers.

STRATEGY D:

Identify alternative financial options and other resources available for cancer care for uninsured or low-income cancer patients.

Rationale

Finances are often a barrier to obtaining adequate treatment. To people on a fixed income, lack of insurance or a high deductible may make these barriers insurmountable. According to the 2004 BRFSS, 10.6 percent of the survey respondents reported they had no health insurance. However, this figure may be higher since the BRFSS notes that it is difficult to obtain accurate estimates of the uninsured and underinsured.

Outcomes

1. Identified financial barriers to cancer treatment.
2. Available community resources will be identified and maximized.
3. Available resources from voluntary agencies will be identified and maximized.
4. Available resources from government-funded programs will be identified and maximized.
5. An updated list of these resources will be made available periodically through the Iowa Department of Public Health.
6. Physicians will be aware of and possess skills to refer patients to financial assistance programs or indigent drug programs.
7. Improved quality of life and survival rates of cancer patients.

STRATEGY E:

All cancer patients in Iowa should receive consultation or care at a facility associated with a program accredited by the American College of Surgeons Commission on Cancer.

Rationale

Delivering state-of-the-art cancer care often requires input from a variety of specialists. The Commission on Cancer accredits cancer programs that provide consultation and cancer care. Such accreditation will help assure cancer patients they are receiving quality care.[49]

Outcomes

1. More cancer care programs will seek accreditation from the Committee on Cancer.
2. More cancer patients will receive consultation or care from programs accredited by the Committee on Cancer.

[49] For more information about the Commission on Cancer, visit: www.facs.org/cancer/coc/cocar.html

GOAL 4:
ASSURE THE QUALITY OF LIFE OF EVERY CANCER SURVIVOR IS THE BEST IT CAN BE.

According to the American Cancer Society, cancer affects an estimated 1 in 3 individuals in their lifetime, either through their own diagnosis or through that of a loved one. In the past, the term "cancer survivor" described someone who did not have cancer five years after diagnosis. Today, the definition of cancer survivorship has been expanded. Survivorship begins at the time of diagnosis and continues through the balance of life. Family members, friends, and caregivers who are impacted by this experience are also considered cancer survivors.

The *National Action Plan for Cancer Survivorship* notes that survivors face numerous physical, psychosocial, social, spiritual, and financial issues throughout their diagnosis, treatment, and beyond. The ***Consortium*** uses the main goals outlined in the *National Action Plan for Cancer Survivorship* to frame this section.[50]

Priority Strategy

Priority strategy as determined by the full ***Consortium*** for this goal is:

- Increase awareness of quality of life issues and skills to effectively engage survivors in making decisions related to treatment and quality of life. *(Goal #4, Problem #1, Strategy A)*

[50] The *National Action Plan for Cancer Survivorship:* www.cdc.gov/cancer/survivorship/overview.htm

Cancer Problem #1:

The *National Action Plan for Cancer Survivorship* notes that cancer survivors are faced with difficult decisions at every stage of living with, through, and beyond cancer. Experts note that increasing awareness of these issues among survivors, providers, and the general public will improve outcomes for all.

The *National Action Plan for Cancer Survivorship* identifies as one of its main goals the promotion of appropriate management and follow-up care for cancer survivors, as a means to maximize the quality and length of their lives.[51]

STRATEGY A:

Increase awareness of quality of life issues and skills to effectively engage survivors in making decisions related to treatment and quality of life.

Rationale

A recommended strategy within the *National Action Plan for Cancer Survivorship* is to disseminate public education programs that empower cancer survivors to make informed decisions. The informed decision-making process will help survivors participate fully in their care and help physicians understand the attitudes and values of their patients.

Outcomes

1. Increased understanding of quality of life issues by health care providers.
2. Increased communication between patients and health care providers on quality of life needs.
3. Increased treatment options based upon patient choices and goals with regard to their quality of life definition.

[51] A National Action Plan for Cancer Survivorship goal. See the plan online at : www.cdc.gov/cancer/survivorship/overview.htm

STRATEGY B:

Improve the level of cooperative/shared decision-making in defining quality of life and develop a plan to increase patient/caregiver awareness of the issue.

Rationale

A growing body of research shows that when patients are well-informed and play a significant role in deciding how they are going to manage their health, the results are more positive. Informed patients feel better about the outcomes of the decision-making process and are therefore more likely to follow their providers' recommendations.[52] Additional research studies demonstrate that patients who assume an active role in treatment decision-making have significantly higher quality of life 3 years later than patients who defer to their oncologists.[53]

Outcomes

1. Each patient's definition of quality of life will be known and respected.
2. Treatment options will be based upon patient choice and goals regarding quality of life.
3. Increased communication between patients and health care providers.
4. Decreased inappropriate decisions made by the patient due to inadequate information.

STRATEGY C:

Support health care providers, cancer survivors, and caregivers in developing a follow-up plan to cancer treatment.

Rationale

According to a recent Institute of Medicine (IOM) report, Americans who survive cancer treatment find themselves without an organized system for maintaining their physical and mental health in the long term.[54] The IOM notes that this transition from active treatment to post-treatment care is critical to long-term health; a plan is essential so that routine follow-up visits become opportunities to promote a healthy lifestyle, check for cancer recurrence, and manage lasting effects of the cancer experience.

Outcomes

1. Cancer patients and the physicians providing post-treatment care will have increased knowledge of the cancer type, treatment, and their potential consequences as well as recommendations for future care, preventative practices, and other supportive services available.
2. Follow-up care for cancer survivors will improve.
3. Cancer patients will feel more supported in their post-treatment phase of survivorship.

[52] *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* page 22

[53] Thomas F. Hack, et al, (2006). Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer, *Psycho-Oncology*, 15(1), 9-19, and Charles, Cathy, et al. (2004). "Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach." *Health Expectations* 7(4), 338.

[54] "From Cancer Patient to Cancer Survivor: Lost in Transition" Institute of Medicine 2005. www.iom.edu/?id=31512

Cancer Problem #2:

Pain and symptom management are a consistent issue for cancer patients. Inadequate management of these issues can damage quality of life of the cancer survivor, whether he or she is in active treatment, is post-treatment, or at the end of life. A main goal of the *National Action Plan for Cancer Survivorship* is to minimize preventable pain, disability, and psychosocial distress for those living with, through, and beyond cancer.

STRATEGY A

Support improved pain management initiatives throughout the state for persons in non-hospital based/hospice settings.

Rationale

Pain and symptom management are a prerequisite to realizing the goal of improved quality of life. Good symptom management helps to create and preserve opportunities for growth during times of illness, caregiving, and grief, for people who are dying as well as for their families.

Issues such as under-treatment of cancer symptoms, treatment side effects, and life-altering problems are not uniformly recognized and addressed within the medical community. Pain assessment and treatment are not consistent across the state.

Outcomes

1. Increased use of measurement and documentation of pain and symptom management.
2. Increased pain management information for physicians.
3. Improved pain management for patients.
4. Patients will be educated regarding pain, use of pain medications, use of complementary methods for pain control, and treatment of side effects for pain management.
5. Symptom management and assessment of those in treatment, those who have completed treatment, or those opting for no further treatment will be consistently addressed and managed.

Cancer Problem #3:

According to the *National Action Plan for Cancer Survivorship*, a diagnosis of cancer is a threat to a person's physical, psychological, social, spiritual, and economic well-being. The various stages of cancer survivorship—diagnosis, treatment, and post-treatment or end-of-life care—can deprive persons of their independence and disrupt the lives of family members and other caregivers. Therefore, supporting cancer survivors in accessing the resources and the family, peer, and community support they need for coping with their disease is necessary.

STRATEGY A:

Coordinate resources to support the needs of cancer patients who have completed treatment, particularly addressing physical, emotional, and financial outcomes.

Rationale

The Institute of Medicine's report on cancer survivorship notes that cancer patients who complete their treatment often do not recognize the long-lasting effects of the cancer and its treatment. Support during this transition from "cancer patient to cancer survivor" is critical for the long-term health of the individual.

Outcomes

1. Improved access to resources for cancer survivors.
2. Improved quality of life for those cancer survivors utilizing support services.
3. Improved long-term health outcomes for cancer survivors.

STRATEGY B:

Increase patient and family awareness of programs and resources available to address the needs of the patient and their caregiver/family.

Rationale

One dimension of the suffering caused by cancer is the financial burden placed on patients and their families because of the high costs of treatment, which may not be completely covered by insurance, and the loss of income and employment caused by a prolonged illness. Increased awareness of programs to support cancer patients in need will alleviate emotional and financial distress.

Outcomes

1. Increased family awareness and use of financial programs and resources that are available.
2. Use of available external resources will be implemented prior to total depletion of personal resources.
3. Lessened perception of stigma attached to receiving financial help.

STRATEGY C:

Increase community awareness of the impact of cancer and its treatment on the caregiver.

Rationale

The Family Caregiver Alliance estimates that there are 300,000 caregivers in Iowa age 18 years and older who provide unpaid care to an adult family member or friend.[55] Following "old age," cancer is the most frequent need cited for care giving.[56]

Unfortunately, researchers have documented that caregivers who carry the heaviest responsibility are more vulnerable to sacrificing their own health, financial security, and quality of life in the process of caring for their loved one. Suffering experienced by primary caregivers is a problem that is poorly recognized by health care providers, policymakers, the general community, and governmental agencies.

Outcomes

1. Increased caregiver use of programs and resources available to assist them.
2. Improved health, stability, and quality of life of caregivers.

STRATEGY D:

Educate caregivers on the importance of taking care of themselves.

Rationale

According to several research studies, family caregivers tend to put the needs of the ill person ahead of their own, often forgoing or delaying their own health care.[57] Care giving is even associated with increased caregiver mortality.[58]

Outcome

1. Caregivers will become educated to recognize the importance of taking care of themselves and will seek time for respite.

[55] Iowa State Profile, "The State of States in Family Caregiver Support," Family Caregiver Alliance, National Center on Caregiving. www.caregiver.org/caregiver/jsp/content/pdfs/state_profile_ia.pdf

[56] "Care giving in the U.S." AARP and the National Alliance for Care giving. April 2004. www.aarp.org/research/reference/publicopinions/aresearch-import-853.html

[57] Rabow, Michael, Joshua Hauser, and Jocelia Adams. (2004). "Supporting Family Caregivers at the End of Life," *JAMA*. 291(4).

[58] Siegel, K, Raveis VH, Houts P, Mor V. (1991) Caregiver Burden and unmet patient needs. *Cancer*. 68:1131-1140.

GOAL 5:
MOVE RESEARCH FINDINGS MORE QUICKLY INTO PREVENTION, TREATMENT AND CONTROL PRACTICES.

Cancer medicine is evolving rapidly. Clinical trials are the cornerstone for finding the best treatment, prevention, detection, and cure for cancer. Unfortunately, many barriers to participation in clinical trials exist. While 70 to 80 percent of pediatric cancer patients participate in clinical trials, currently only 3 percent of adult cancer patients participate in clinical trials. Even fewer minority and older patients participate. Many trials never obtain a sufficient number of patients to provide scientifically valid conclusions. Other trials never get beyond the concept stage because of insufficient number of participants. Each incomplete trial represents a failed opportunity to improve cancer control. It is estimated that at least 10 to 15 percent of adult cancer patients must participate in trials to move research forward more rapidly.

Priority Strategy

Priority strategy as determined by the full ***Consortium*** for this goal is:

- Encourage insurance carriers to provide coverage through insurance plans for clinical cancer trial participation and cover costs of routine patient care when enrolled in a clinical cancer trial. *(Goal #5, Problem #1, Strategy A)*

Cancer Problem #1:

Significant financial barriers exist to participation in clinical trials. Currently, most research trials cover the cost of the investigational part of the trial, but participants often face significant expenses for routine patient care—physician and hospital fees and laboratory tests. Overall, there is a lack of clarity of what insurance will and will not cover in a clinical trial.[59] Many insurance programs and third-party payers refuse coverage for treatments, diagnostic procedures, and prevention initiatives under investigation, as well as any additional costs related to the trial.

STRATEGY A:

Encourage insurance carriers to provide coverage through insurance plans for clinical cancer trial participation and cover costs of routine patient care when enrolled in a clinical cancer trial.

[59] www.cancer.gov/clinicaltrials/understanding/insurance-coverage

Rationale

Since 2000, Medicare has been required to reimburse all routine patient care costs for participation in clinical trials.[60] While this has increased Medicare enrollees' access to clinical trials, there are still financial barriers for those covered by Medicaid, private insurance, and the uninsured. Individuals participating in trials are required to pay out-of-pocket health care costs, which discourages participation. Ensuring that routine patient care costs will be covered by health insurance is the first step in encouraging greater participation in clinical trials.

Outcomes

1. More insurers will cover the costs of routine patient care for patients enrolled in cancer clinical trials.
2. More Iowans will participate in cancer clinical trials.

STRATEGY B:

Gather and make public information from various insurance carriers about insurance coverage for clinical cancer trial participation and whether or not they cover costs of routine patient care when enrolled in a clinical cancer trial.

Rationale

Awareness of what health insurance carriers in the state cover for clinical trials will help cancer patients and the public make informed decisions, not only about whether or not to participate in cancer clinical trials, but also which insurance carrier to select.

Outcomes

1. Iowans will be informed of what their insurance carriers will and will not cover regarding participation in cancer clinical trials.
2. Public knowledge regarding insurance coverage for clinical trials will help to encourage insurance carriers to increase coverage.
3. More Iowans will participate in cancer clinical trials.

[60] www.cms.hhs.gov/ClinicalTrialPolicies/

Cancer Problem #2:

There is a concern on the part of some potential research subjects that medical information, particularly genetic information, obtained as part of clinical cancer trials could negatively affect their current or future insurability, or if an inherited factor is identified, on the health or life insurability or employability of their family members. This fear limits participation in important and promising approaches to cancer prevention, screening, and treatment.

According to the Iowa Public Health Association (IPHA), anxiety about genetic privacy is a perceived barrier to genetic testing and participation in clinical trials in this state.[61] The IPHA reports research that indicates that two-thirds undergoing genetic testing worry about insurance issues. Of those, 44 percent worry about loss of insurance due to testing, and 33 percent resist changing jobs due to fear of losing health insurance.

STRATEGY A:

Policies should be enacted for all Iowa insurance carriers and all Iowa employers that specifically prohibit the following actions.

For insurance carriers:

1. Prohibit requesting or requiring collection or disclosure of genetic information without prior specific written authorization for that particular test from the individual;
2. Prohibit using genetic information or an individual's request for genetic services to deny or limit any coverage to that individual or their relatives;
3. Prohibit establishing differential rates or premium payments based on genetic information or an individual's request for genetic services; and
4. Prohibit releasing genetic information without specific, prior, and written authorization by the individual.

For employers:

1. Prohibit using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits, or termination of employment;
2. Prohibit requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment;
3. Prohibit accessing genetic information contained in medical records released by individuals or their relatives as a condition of employment, in claims filed for reimbursement for health care costs or other services; and
4. Prohibit releasing genetic information without specific, prior, and written authorization by the individual.

[61] Iowa Public Health Association 2006 Advocacy Statement "Genetic Discrimination." Page 13. www.iowapha.org/Public_Health_Advocacy/IPHA_2006_Advocacy_Statements.pdf

Rationale

Enforceable policies for insurers and employers would promote the protection of genetic information and the avoidance of discrimination based on genetic information.

The preferred approach for enacting such policies is through voluntary action on the part of insurance carriers and employers. Failing that, legislative and regulatory approaches should be enacted.

Outcomes

1. Clear policies that Iowa insurance carriers and employers will not practice genetic discrimination would decrease concern on the part of potential clinical trials subjects that results obtained as part of clinical cancer research programs could affect insurability.
2. Increased participation in clinical trials that involve genetic testing.

Cancer Problem #3:

The majority of cancer patients lack knowledge of options regarding cancer clinical trials. According to a poll conducted in 2000, around 85 percent of cancer patients surveyed were unaware or unsure that participation in clinical trials was an option, though 75 percent said they would have been willing to enroll had they known it was possible.[62]

STRATEGY A:

Develop Iowa-specific companion materials for Iowans recently diagnosed with cancer that can be used along with nationally developed clinical trials education materials. The companion materials should provide basic, factual information in a low-literacy format. Materials should be distributed free-of-charge to patients and providers in Iowa.

Rationale

An Iowa-specific handbook and video would address the questions and concerns unique to the state's population and resources. Targeting these barriers would facilitate a discussion between the health care provider and patient regarding clinical trials participation.

Outcomes

1. Increased number of patients exposed to consistent information regarding clinical trials.
2. Increased number of patients choosing clinical trials as a quality treatment option.

[62] Harris Interactive. Health Care News, Vol. 1, Issue 3. Jan 22, 2001
www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews2001Vol1_iss3.pdf

Cancer Problem #4:

Information about clinical trial availability and access is not uniform. Since clinical trials are sponsored by many different entities and take place at hospitals and clinics interspersed throughout the state, consistent information related to clinical trials across Iowa is not readily available.

STRATEGY A:

Maintain and expand a central website that is updated regularly and includes information about open clinical trials across Iowa, as well as information about who to contact concerning additional information and potential eligibility.

Rationale

Maintaining a single site to distribute information related to clinical cancer trials will continue to assist individuals who are searching for clinical trials in Iowa and connect them to the various entities that offer those trials.[63]

Outcomes

1. Information related to clinical trials will be readily available to both physicians and patients.
2. Enrollment in clinical trials will increase.

[63] Currently, the ICCCC web portal lists cancer clinical trials: www.canceriowa.org/trials/links

CROSSCUTTING STRATEGIES

The previous goal-oriented sections outlined strategies and outcomes associated with each specific goal (e.g., tobacco prevention and control strategies as part of achieving the plan's "prevention" goal). It is readily evident from these detailed goal discussions that there are related strategies that address multiple goals. The ***Consortium*** members were asked to identify and summarize these for use during the implementation of the plan to optimize the opportunities for integration and resource management and to avoid duplication and competition for resources. In addition, ***Consortium*** members were asked to identify any unique, additional strategies for consideration in setting overall priorities. These crosscutting discussions covered the following topics:

- Advocacy.
- Public awareness.
- Professional education.
- Financial issues.
- Coordination with other organizations and state agencies.
- Surveillance, data, and evaluation.

In addition, each goal-oriented work group identified issues related to population disparities throughout the planning process; disparities are also addressed in this section as a crosscutting issue. The creation of web-based information resources is also discussed.

Each of the following sections includes an abbreviated listing of the goal-oriented strategies for consideration during implementation. Each section also includes some options for combining strategies and any new strategies that were identified.

Advocacy

These strategies include both legislation and voluntary policy development.

- Increase the state excise tax on tobacco products.
- Eliminate public exposure to secondhand smoke.
- Increase funding for Iowa's tobacco prevention program to make it comprehensive in scope.
- Make policy changes to reduce harmful sun exposure among children and adolescents.
- Advocate for policy changes to require radon testing of all Iowa homes during or prior to their sale and that new construction includes radon resistant techniques.
- Increase public funding for cancer early detection.
- Support improved pain management initiatives throughout the state for persons in non-hospital based/hospice settings.
- Advocate for policy changes by insurers and employers to assure coverage for cancer clinical trials participation and to prohibit any form of genetic discrimination.

Public Awareness

These strategies include efforts to provide information and education to populations at large.

- Increase awareness of current tobacco use cessation programs.
- Increase awareness of the relationship of obesity, physical activity and nutrition to cancer through public education.
- Support *Lighten Up Iowa*, a statewide campaign on obesity.
- Increase awareness of sunburn as a risk factor for skin cancer.
- Educate Iowa youth about harmful ultraviolet light exposure through tanning devices.
- Increase awareness of the link between alcohol use and some cancers.
- Increase awareness of genetic risks for cancer and the availability of personalized cancer risk assessment and genetic counselors.
- Increase general awareness of cancer screening and early detection guidelines and personal responsibility for adherence to guidelines.
- Increase knowledge about cancer disease process, treatment options, and treatment costs, including communication with providers and entrance into clinical trials as a treatment option.
- Increase awareness of quality of life issues and skills to effectively engage survivors in making decisions related to treatment and quality of life.
- Increase community awareness of impact of cancer and its treatment on the caregiver.
- Increase patient and family awareness of resources to address the needs of the patient and their caregiver/family.
- Educate caregivers on the importance of taking care of themselves.
- Increase awareness level of cancer patients regarding clinical trials, enrollment in specific trials, and about the coverage by individual health insurance carriers for clinical trial participation.
- Maintain and expand a central website for cancer information, clinical trials availability and other resources.

Professional Education

These strategies include educational efforts targeting primary care practitioners, specialists, and professional training programs.

- Encourage and recognize Continuing Medical Education and Continuing Education Units on cancer-related topics among Iowa's health professional associations.
- Provide and promote education among primary health care providers regarding prevention, early detection and screening, tobacco use cessation, alcohol use, treatment options, quality of life issues, cancer survivorship, palliative care, clinical trials, and other current research.
- Educate health care providers on their roles in educating patients and family members about the topics noted in the bullet above.
- Educate health care providers about resources available to underserved cancer patients regarding screening/early detection and treatment.
- Increase the ability of health care providers to deliver culturally sensitive care in the languages spoken by Iowa's diverse populations.

- Support health care providers, cancer survivors, and caregivers in developing a follow-up plan to cancer treatment.
- Develop professional education programs on clinical trials participation and linkages.
- Maintain and expand a central website for cancer information, clinical trials availability, and other resources.

Financial Issues

These strategies include the cost of cancer care, provisions for the economically disadvantaged, and issues related to consistency in insurance coverage.

- Increase funding resources for comprehensive cancer control, including the ancillary costs of patient care.
- Increase funding for Iowa's tobacco prevention program to make it comprehensive in scope.
- Decrease the financial barriers that restrict Iowans' abilities to access early detection cancer screenings through increased public and provider knowledge of insurance plan coverage options and other non-traditional resources, including free services.
- Identify alternative financial options and other resources available for cancer care for uninsured or low-income cancer patients.
- Coordinate resources to support the needs of cancer patients who have completed treatment (i.e. "survivors"), particularly addressing the physical, emotional, and financial outcomes.
- Distribute information related to clinical trials to health insurance carriers and encourage them to develop policies that provide for routine patient care costs during clinical trials.
- Develop an approach convincing insurance providers of the relevance of clinical trials and the benefits of providing coverage voluntarily.

Coordination with Other Organizations and State Agencies

These strategies underscore the importance of coordination and cooperation among agencies to deal with cancer in a comprehensive manner. Partnerships with other organizations and coalitions—both inside and outside of the ***Consortium***—will help maximize resources and reduce duplication.

- Increase awareness of and participation in current programs for smoking and other tobacco product cessation.
- Support the efforts of Iowans *Fit for Life*, a CDC-sponsored program charged with the creation of a comprehensive state plan to address physical activity and nutrition to prevent obesity and other chronic diseases.
- Support *Lighten Up Iowa*, a statewide campaign to reduce the prevalence of overweight and obesity among Iowans by increasing physical activity and improving food choices.
- Develop an occupational safety plan that identifies skin protection strategies for seasonal, outdoor workers.
- Support the programs and activities of the Iowa Air Coalition and IDPH that promote radon mitigation in homes.
- Support the goals of the Governor's Office of Drug Control Policy's Drug Control Strategy.

- Utilize cancer support groups, HMOs, insurance carriers, the ACS, the ICCCC website, and other organizations for exchanging information among cancer patients, families/caregivers, survivors, and physicians.
- Coordinate with existing agencies to provide transportation for cancer patients to/from cancer treatment facilities (e.g., the ACS and the Area Agency on Aging)
- Support improved pain management initiatives throughout the state for persons in non-hospital based/hospice settings.

Surveillance, Data, and Evaluation

These studies and strategies include new and ongoing surveillance needs as well as "assessments" of current practices and intervention feasibility studies.

- Assess the degree to which state-required prior approvals are a barrier to screening and access to care.
- Periodically evaluate evidence-based screening and treatment guidelines.
- Maintain a statewide registry for cancer incidence and follow up and assist in supporting local cost sharing.
- Maintain the Behavioral Risk Factor Surveillance System and enhance the youth survey to include weight, tanning practices, etc.
- Improve and maintain the timeliness in death certificate reporting.
- Periodically assess data, surveillance, and evaluation needs and bring together experts on various databases to discuss how these needs can be met.
- Assess the geographic distribution of health care providers and its relevance to cancer control goals.
- Identify gaps in treatment options and resources.
- Identify alternative financial options and other resources available for cancer care for uninsured or low-income cancer patients.
- Gather information from health insurance providers on coverage for clinical trials participation.
- Maintain and expand a central website that is updated regularly and includes information about open clinical trials across Iowa, as well as information about who to contact concerning additional information and potential eligibility.

Furthermore, the ***Consortium*** is committed to an ongoing, comprehensive evaluation that not only measures the outcomes and effectiveness of the work that is being done, but also addresses the way in which it is done—i.e. evaluating the ***Consortium*** itself. Through its partnership with The University of Iowa College of Public Health, Iowa Center for Evaluation Research, the ***Consortium*** is uniquely positioned to constantly receive feedback and recommendations that will allow it to function more effectively and efficiently.

Population Disparities

There is no question that there are disparities in the cancer experience among various populations within Iowa. These disparities cover a broad range of population differences including geography, age, socioeconomic status, and racial, ethnic, and cultural backgrounds. The national Healthy People 2010 initiative of the U.S. Department of Health and Human Services has as one of its major goals the elimination of such disparities.

The ***Consortium*** supports this goal and in the Guiding Principles to this plan commits to addressing disparities even as it attempts to address the entire state population.

This plan identifies a number of specific issues related to disparities (e.g., language and cultural barriers to early detection services) and proposes strategies for dealing with them. Nevertheless, the ***Consortium*** feels strongly that the implementation of every strategy in this plan must account for any associated cancer-related disparities. Importantly, the commitment embedded in this plan is to change the experience of all Iowa's diverse population groups such that each achieves the same level of cancer outcomes as that achieved by the population group with the best experience.

The ***Consortium*** plans to demonstrate this commitment by convening a task force to address the issue of disparities within the cancer plan. This group will develop a companion report that will include data from current projects, such as the Colorectal Cancer Monograph and the Community Conversations about Cancer in diverse populations within Iowa. The goal will be to define what disparities there are in the state and identify strategies to address them effectively.

Web-Based Information Resource(s)

Several strategies have been proposed in this plan for developing web-based information resources. These are all intended to make it more efficient and user-friendly for the public, cancer patients, and health professionals to search for and access a wide variety of Internet-based information that can aid in making more informed decisions regarding cancer issues.

The ***Consortium*** has developed a web portal, www.canceriowa.org, to accomplish these strategies. As Iowa's source for authoritative cancer information, the web portal is a valuable tool for cancer patients, health care providers, and the general public. The ***Consortium*** will continue to support the website, maintaining and expanding it where possible. See Appendix C for additional information about the website.

IMPLEMENTATION

In 2001, a group of Iowans concerned about cancer came together to begin working on *The Face of Cancer in Iowa*, the legislative mandated report that details the burden of cancer on the people of Iowa. In response, a broad group of Iowans, including health professionals, researchers, and representatives of many state and community organizations have been working together since then to produce and implement this plan. In all, more than 100 individuals from 50 agencies and organizations and communities across the state have volunteered their time to work together to control cancer.

To assure continued implementation of this plan, it is recognized that many organizations representing the private, government, and not-for-profit sectors of Iowa must work together. The ***Consortium*** believes that successful implementation of the plan requires the following approaches:

- Sustaining the ***Iowa Consortium for Comprehensive Cancer Control*** as a focal point for oversight of the plan's implementation and a vehicle for increased involvement of people and organizations from across the state.
- Assuring accountability for implementation of the plan.
- Bringing the plan to the attention of key decision-makers and the citizens of Iowa and promoting awareness of it on a regular and ongoing basis.
- Developing a budget to describe the cost of fully implementing a comprehensive cancer control program.
- Evaluating progress against the plan and updating/adjusting it based on the degree to which its goals and outcomes are being achieved.

Each of these approaches is presented in more detail in the remainder of this section.

Sustaining and Growing the Consortium

The people who made up the group developing this plan did so initially as the ***Iowa Consortium for Comprehensive Cancer Control*** whose task was to produce a statewide, comprehensive cancer control plan. After completing the plan, it is the opinion of this group that the Consortium should continue to exist with a shift in its responsibilities to include two new tasks: providing a focal point for assuring implementation and periodically assessing progress against it. Moreover, it is the belief of current ***Consortium*** members that successful implementation will require increasing numbers of organizations from across the state and that provisions for inviting new members and sustaining their interest and involvement are required.

The initial structure of the ***Consortium*** was quite simple. A Steering Committee was selected of a few key, cancer-concerned individuals who were willing to volunteer their time not only to participate in the planning effort, but also to play a leadership role in organizing and overseeing the process. The work of the ***Consortium*** to date was also supported by both monetary and staff support from the Iowa Department of Public Health and the American Cancer Society, Midwest Division. A joint position, funded by the CCC Program and the National Cancer Institute's Cancer Information Service Partnership Program, has brought additional staff to the Consortium.

The structure following completion of the plan remains essentially the same with the exception that implementation groups and standing committees have been established with two charges:

1. Implement the priorities selected by the full ***Consortium***; and
2. Implement other strategies identified in the plan as opportunities arise to do so.

Several implementation groups and standing committees have been formed, as well as an Executive Committee.

Assuring Accountability

There are two primary mechanisms for assuring accountability for implementation of this plan.

- Assuring that a critical mass of ***Consortium*** members are actively engaged in the implementation process for each priority; and
- Periodically assessing and reporting on progress against the plan (described later in this section).

At the plan ratification meeting of the ***Consortium***, participants were given the opportunity to join an implementation group. The implementation groups formed have a substantial and critical mass of participants to initiate implementation of their assigned priorities. It was gratifying to note that participants readily agreed to participate in implementation groups and that they also readily suggested additional individuals/organizations from outside the current ***Consortium*** to be recruited for the various groups. A membership audit was completed in 2005 that identified gaps in the current membership. The Membership and Nominating Committee will develop a plan for strategic recruitment to address these gaps.

Raising Awareness of the Plan among Key Decision-Makers and the Public

It is the strong belief of the ***Consortium*** that the successful implementation of this plan will depend on widespread visibility and awareness of the plan throughout Iowa. Strategies for promoting the plan include an initial, public kick-off event, media coverage, and expanding the ***Consortium*** by recruiting major, recognized decision-makers. In addition, the ***Consortium*** made plans for publication of the plan and distribution throughout the state to interested parties, potential ***Consortium*** members, and policy makers. There are also plans for assuring the Iowa Legislature receives copies since it was their mandate in 2001 that led to the development of *The Face of Cancer in Iowa*, which in turn led to the development of the ***Consortium*** and this plan.

It is recognized that a one-time, kick-off event unveiling the plan, no matter how successful, will not sustain public interest and involvement in the plan and its implementation. Plans are also being developed to keep the plan in the public eye on a regular and ongoing basis. As implementation successes are achieved (e.g., obtaining grant funding for specific priorities, successful enactment of certain policies, and public positions on key cancer issues taken by the ***Consortium***) they will also be announced. Importantly, the ***Consortium***, at least annually, will report to the public on progress against the plan and the status of the cancer burden in Iowa. In 2006, the ***Consortium*** will focus on promotional efforts to increase support and resources for its efforts. The revised cancer plan and trainings to create a uniform message will assist in this effort.

Development of a Budget

In the coming year, the ***Consortium*** will collaborate with the non-profit organization C-Change to develop a budget that describes the full cost of comprehensive cancer control in Iowa. This document will assist with promotion of the plan, as well as help legislators understand the true cost of controlling cancer in Iowa.

Evaluation of Progress

There is a need to assess progress against the plan – both in terms of achieving the goals outlined in the plan related to the cancer burden and in terms of progress made towards implementation of each of the priority strategies in the plan.

A standing committee of the ***Consortium*** has been established for Data and Evaluation and will help design the specific approach for evaluation of progress and the plan.

The ***Consortium*** has viewed this plan, from its inception, as a "living" document. The plan outlines a broad vision and goals and identifies priority strategies for implementation. When progress is assessed against the plan, it is expected that what is accomplished and learned from the data will change the direction and perhaps even the strategies employed. Therefore, based on each progress review, the plan will be updated, and as appropriate, will be altered to reflect new circumstances, changing priorities, and new opportunities.

Importantly, as noted above, there is a need for the public, decision-makers, and ***Consortium*** members to be aware of progress made on an ongoing basis. An annual review of progress will be conducted by the ***Consortium*** and reported widely, along with any changes in the plan based on the results of the review.

As previously stated, evaluation of the projects of the ***Consortium,*** as well as the way in which the ***Consortium*** works, is a top priority. The ***Consortium*** feels that an ongoing commitment to evaluation will allow it to work more effectively and efficiently. The evaluation contractor for the ***Consortium*** provides evaluation results and data to the Executive Committee and the ***Consortium*** on a consistent and timely basis throughout the year. This evaluation has produced recommendations and data that the Executive Committee utilizes as the ***Consortium*** moves into the future.

SPECIAL FOCUS:
CANCER HEALTH DISPARITIES IN IOWA

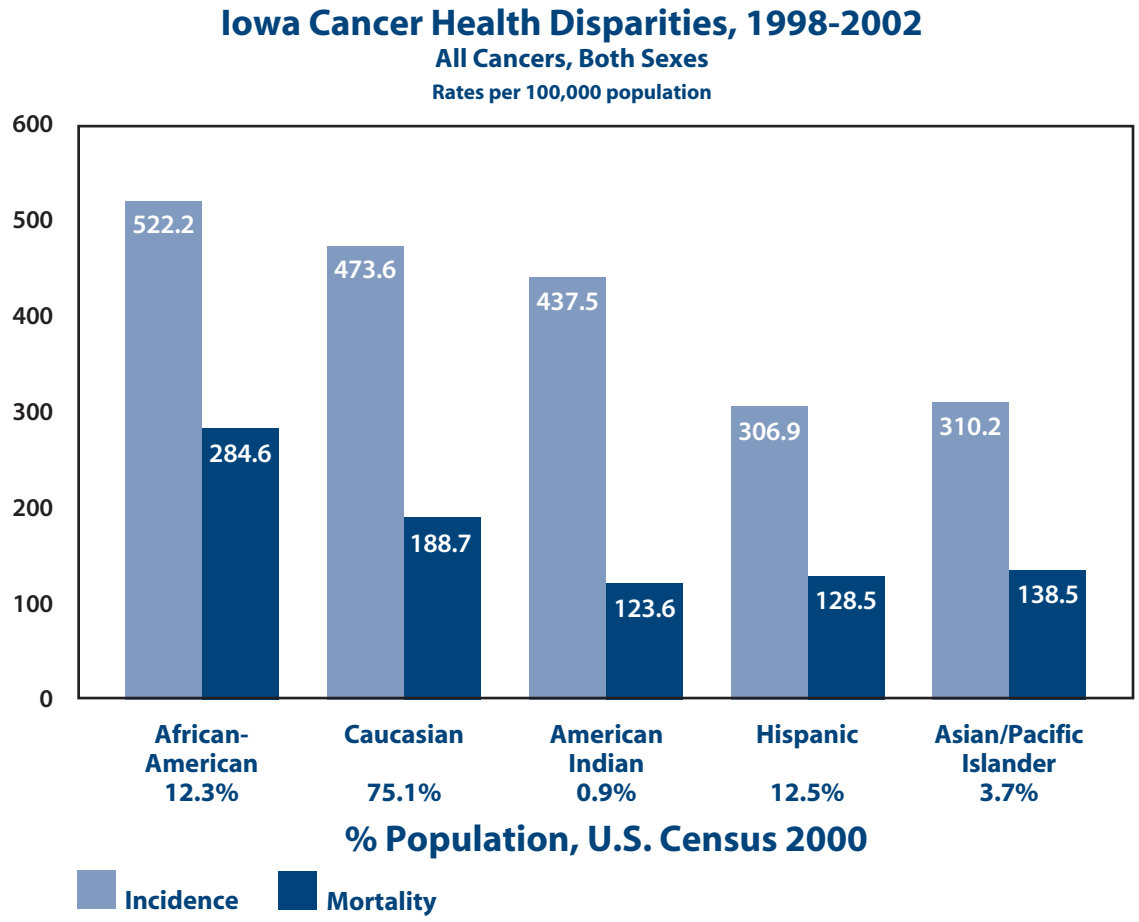
Despite advances in cancer prevention, detection, and treatment, there are still individuals and groups that suffer a disproportionate burden of cancer. These differences—a higher incidence of cancer, higher mortality rate, or lower survival rate—are described as health disparities.

Disparities can be caused by a number of factors, including:

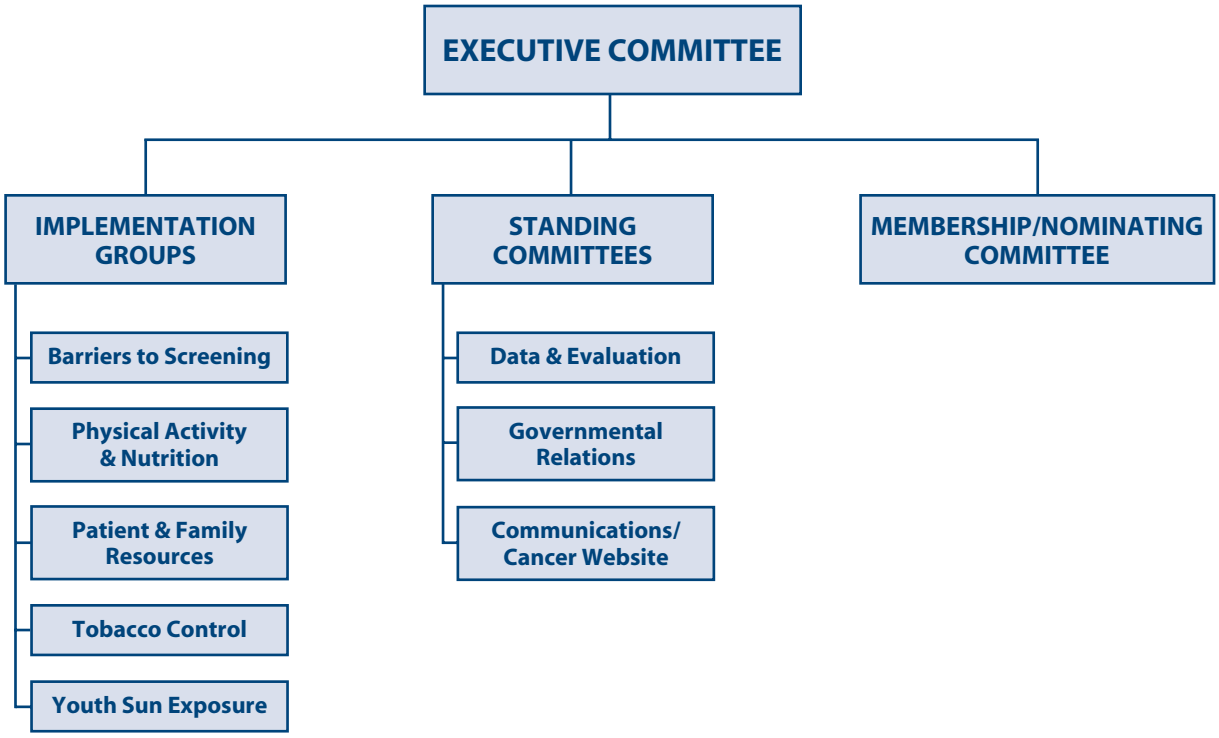
- Geographic location such as rurality.
- Insurance status—uninsured, under-insured.
- Socioeconomic status—educational attainment, income, class.
- Racial/ethnic minority groups.
- Disability status.
- Age.
- Cultural differences.

In Iowa, many cancer health disparities exist. For example, the figure below compares cancer incidence rates among Iowa's various racial/ethnic groups.

The *Consortium* will convene a task force to explore this issue further, developing a companion document to define and address disparities in the state of Iowa.



APPENDIX A
IOWA CONSORTIUM FOR COMPREHENSIVE CANCER CONTROL



APPENDIX B
ORGANIZATIONS INVOLVED IN COMPREHENSIVE CANCER CONTROL IN IOWA

- Alegent Health Immanuel Medical Center
- American Cancer Society, Midwest Division
- American Lung Association
- Association of Pediatric Oncology Nurses
- Broadlawns Medical Center
- Calhoun County Department of Public Health
- Central Iowa Tobacco-Free Partnership
- Clean Air For Everyone (CAFE)
- Family Planning Council of Iowa
- Genesis Medical Center
- Healthy Linn Care Network
- Iowa Department of Public Health (IDPH)
  - Bureau of Health Care Access
  - Bureau of Oral Health
  - Bureau of Chronic Disease Prevention & Management
  - Comprehensive Cancer Control Program
  - Division of Health Promotion and Chronic Disease Prevention and Management
  - Healthy Child Care of Iowa
  - Nutrition Education Network
  - Office of Minority Health
  - Division of Tobacco Use Prevention & Control
  - Tuberculosis Control Program
- Indian Health Service—Meskwaki Clinic
- Intercultural Cancer Council
- Iowa Academy of Family Physicians
- Iowa Attorney General's Office
- Iowa Breast Edu-Action
- Iowa Commission on Substance Abuse
- Iowa Department of Elder Affairs
- Iowa Department of Education
- Iowa Department of Human Services
- Iowa Foundation for Medical Care
- Iowa Games
- Iowa Health Systems
- Iowa Hospice Organization
- Iowa Hospital Association
- Iowa House of Representatives
- Iowa Parish Nurse Network
- Iowa Pharmacy Association
- Iowa State University
- Iowa Statewide Poison Control
- Iowa/Nebraska Primary Care Association
- Iowa State University Extension
- Leukemia & Lymphoma Society
- Marshalltown Patient Resource Center
- University of Iowa College of Dentistry
- Mary Greeley Medical Center
- Mercy Regional Cancer Center—Cedar Rapids
- National Cancer Institute's Cancer Information Service
- National Ovarian Cancer Network
- Oncology Nurses Society
- Ottumwa Regional Health Center
- Page County Department of Public Health
- Pottawattamie County Tobacco Prevention Coalition
- St. Luke's Hospital—Cedar Rapids
- State Health Registry of Iowa
- University of Iowa
  - Center for Evaluation and Research
  - College of Medicine
  - College of Public Health
  - Holden Comprehensive Cancer Center
- Wellmark Blue Cross Blue Shield of Iowa

APPENDIX C
SELECTED CANCER DATA SOURCES

BRFSS:

www.idph.state.ia.us/brfss/

The Behavioral Risk Factor Surveillance System (BRFSS) is the largest, continuously conducted telephone survey in the world. It is conducted by states under the guidance of Center for Disease Control and Prevention. The survey is designed to identify and monitor risk factors for chronic diseases and other leading causes of death. The BRFSS is an Iowa-specific surveillance system that surveys adults 18 years and older on self-reported health behaviors. Each month, a random sample of structured telephone interviews is conducted. Questions in the survey relate to nutrition, physical activity, tobacco use, hypertension, blood cholesterol, alcohol use, inadequate preventive health care, and other risk factors. An annual BRFSS report is published. Because the survey is conducted on an annual basis, the continuous use of this system allows analysis of trends over time.

Iowa Cancer Registry:

www.public-health.uiowa.edu/shri/

The Iowa Cancer Registry (ICR) is a population-based cancer registry (part of the State Health Registry of Iowa) that has served the State of Iowa since 1973. The ICR has been a member of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program since its inception in 1973. The goals of the State Health Registry of Iowa are to:

- Assemble and report measurements of cancer incidence, survival and mortality among Iowans;
- Provide information on changes over time in the extent of disease at diagnosis, therapy, and patient survival;
- Promote and conduct studies designed to identify factors relating to cancer etiology, prevention, and control;
- Respond to requests from individuals and organizations in the state of Iowa for cancer data and analyses;
- Provide data and expertise for cancer research activities and educational opportunities.

ICCCC Web Portal:

www.canceriowa.org

The ***Consortium's*** website, www.canceriowa.org, is Iowa's central source for authoritative links to cancer resources in the state and beyond. Knowledgeable cancer information specialists have compiled and verified these resources, to simplify your search for quality cancer information. Learn how to prevent cancer, where to be screened for cancer, how cancers are treated, and what community resources are available.

IDPH Breast and Cervical Cancer Program: Care for Yourself

http://www.idph.state.ia.us/careforyourself/default.asp

Care for Yourself, the Iowa Breast and Cervical Cancer Early Detection Program, is part of a national program to help reduce the number of deaths from breast and cervical cancer. To do this, women must have regular screening tests. Local Care for Yourself Programs help eligible women to receive: clinical breast exams, mammograms, pelvic exams, and Pap tests. Women who are diagnosed with breast or cervical cancer through the Care for Yourself Program receive help in finding treatment. Care for Yourself assists in providing these services to eligible women. Services are directed especially to women between the ages of 40 to 64 years, women age 40 years or below with breast symptoms, minorities, including rural, and rarely or never screened women.

Comprehensive Cancer Program

http://www.idph.state.ia.us/hpcdp/comp_cancer_control.asp

The Comprehensive Cancer Control Program works with the statewide Iowa Consortium for Comprehensive Cancer Control—comprised of over 100 people representing approximately 50 agencies from across the state—on the development and implementation of the state's comprehensive cancer control (CCC) plan. The current plan addresses cancer prevention, early detection, treatment, quality of life, and research. In addition, it includes crosscutting issues related to advocacy, patient education, financial issues, surveillance, data and evaluation, population disparities, and web-based information and resources. The ***Consortium*** is in the process of implementing the state plan. For the current year, the ***Consortium***, through its implementation groups and standing committees, will focus on issues related to tobacco, obesity, youth sun exposure, screening barriers, patient and family resources, genetics, data and evaluation, and an Iowa-based cancer web site. In addition to the activities supporting the ***Consortium*** and implementation of the state plan, the program works on issues and projects specific to colorectal and prostate cancers, as well as skin cancer awareness.

APPENDIX D
REVISION OF THE IOWA CONSORTIUM FOR COMPREHENSIVE CANCER CONTROL'S STATE PLAN

Revision of the state cancer plan began in June of 2005. At that time, the ***Consortium*** met to identify areas needing improvement. The ***Consortium*** formulated and included new strategies, recommended descriptive changes, and created a timeline for completion of the revised plan.

The next step of the revision process was another meeting of the full ***Consortium*** in October of 2005. At this meeting, the chair of the ***Consortium*** led the group through a ranking exercise using the Delphi process to identify the strategies each individual or organization was willing to work on and/or support. The strategies were then prioritized according to ***Consortium*** member votes.

In late October of 2005, the Executive Committee met to process input from earlier discussions and to create a framework for the revised plan. The Executive Committee formed a Writing Committee to provide additional feedback and assigned the partnership program coordinator to update statistical data and strengthen the plan with evidence-based strategies and citations for all data sources.

In preparation for the spring ***Consortium*** meeting, the Executive Committee had a chance to review and provide feedback on the plan. The full ***Consortium*** viewed the working draft of the document both before and during the April 27, 2006 spring meeting. Comments and changes will be ongoing and constant critiques of the plan will be obtained from ***Consortium*** members.