Changing the Face of Cancer in Iowa

A STATE PLAN FOR 2003 - 2005

July 2003

ACKNOWLEDGEMENTS

Changing the Face of Cancer: A State Plan for 2003 - 2005 is the result of a statewide, collaborative initiative, designed to improve the state's cancer prevention and control efforts. The plan was developed through the generosity and interest of many organizations and individuals contributing time, expertise, program resources, and financial support.

The creation of the plan was guided by the Comprehensive Cancer Control Steering Committee. Members of the Steering Committee, recognized for their commitment to the comprehensive cancer control (CCC) initiative, are as follows: Maleka Ahmed, MD, Iowa Medical Society; Jane Condon, RN, BSN, MBA Calhoun County Health Department; Elizabeth Coyte, PA, Iowa Nebraska Primary Care Association; State Representative Ro Foege, Iowa House of Representatives; Jude Igbokwe, PhD, Iowa Department of Public Health; Susan Kell, RN, Iowa Academy of Family Physicians; Jill Myers Geadelmann, BS, RN, Iowa Department of Public Health; Charles Lynch, MD, PhD, State Health Registry, University of Iowa; Pat Ouverson, RN, American Cancer Society, Midwest Division; Molly Veenstra, RN, BSN, Susan G. Komen Breast Cancer Foundation; and George Weiner, MD, Holden Comprehensive Cancer Center.

The Iowa Consortium for Comprehensive Cancer Control served as the driving force in developing Iowa's cancer plan. The members of the Iowa Cancer Consortium, who gave generously of their time and talent, are listed on the inside back cover of this report.

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. Recognition is also given to staff from the Centers for Disease Control and Prevention, specifically Lorrie Graaf, CDC Public Health Advisor, for her expertise in leading Iowa's CCC effort, and Strategic Health Concepts staff, Tom Kean and Erin McBride, for providing technical assistance, support, and guidance during the planning process.

The process of developing a CCC plan has brought together many people and organizations to examine, very broadly and in a concerted effort, the need for improving cancer prevention and control in Iowa. 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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EXECUTIVE SUMMARY

Changing the Face of Cancer in Iowa: A State Plan for 2003 - 2005

Cancer exacts a terrible toll on Iowa, year after year. Last year, some 14,600 Iowans were told they have cancer and approximately 6,300 lost their lives to this disease. That's the bad news. The good news is that research advances have brought us to the point where 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.

But, Iowa has an opportunity to save so many more of our fellow citizens from the consequences of cancer by using already proven techniques for cancer prevention, early detection, treatment and quality-of-life and to continue as an active participant in the nation's cancer research enterprise.

Iowa can significantly change the course of cancer through organizations from the private, government and the not-for-profit sectors working together in a comprehensive, statewide approach to cancer control - something that hasn't happened here before.

In 2001, the Iowa Legislature commissioned a detailed study of the impact of cancer on the state. Their report, *The Face of Cancer in Iowa*, led to the formation of the Iowa Consortium for Comprehensive Cancer Control consisting of more than 100 individuals representing 50 agencies and organizations across the state. The Consortium chose as its first priority to create a comprehensive, statewide cancer plan that would have broad support and participation from cancer-concerned organizations throughout the state. The plan includes 50 strategies for addressing critical cancer problems in Iowa over the next three years. It also prioritizes six of these for implementation beginning in July 2003.

This Executive Summary provides an overview of the plan's vision, goals and initial priorities. The full plan that follows this summary contains many more details including background information on each of the cancer problems addressed and strategies proposed as well as a rationale for each strategy and expected outcomes that will result from successfully implementing them.

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 OCCURING.
- 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 PATIENT IS THE BEST IT CAN BE.
- MOVE RESEARCH FINDINGS MORE QUICKLY INTO PREVENTION AND CONTROL PRACTICES.

Priority Strategies for Implementation Beginning July 2003

- 1. Develop a statewide information resource (i.e., website) to contain a wide variety of critical cancer-control information (e.g., clinical trials availability, provider locations and contact information, and links to other state and national cancer control information sources). The concept is to centralize information access for both the public and health professionals in order to provide an efficient means for informed decision-making.
- 2. Increase the state excise tax on cigarettes by \$1.00, making the total tax per pack \$1.36.
- 3. Maintain a state commitment to an endowment focused on health issues at levels comparable to that which would have been available prior to the securitization of the tobacco-related Master Settlement Funds.
- 4. Policies should be enacted for all Iowa insurance carriers that specifically prohibit the following actions. The preferred approach for enacting such policies is through voluntary action on the part of insurance carriers themselves. Failing that, legislative and regulatory approaches should be enacted.
 - Requesting or requiring collection or disclosure of genetic information without prior specific written authorization for that particular test from the individual;
 - Using genetic information, or an individual's request for genetic services, to deny or limit any coverage to that individual or their relatives;
 - Establishing differential rates or premium payments based on genetic information, or an individual's request for genetic services; and
 - Releasing genetic information without specific, prior and written authorization by the individual.

Policies should also be enacted for Iowa employers that specifically prohibit the following actions. Again, the preferred approach for enacting such policies should be through voluntary action on the part of employers themselves. Failing that, legislative and regulatory approaches should be enacted.

• Using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits or termination of employment;

- Requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment;
- 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
- Releasing genetic information without specific, prior and written authorization by the individual.
- 5. Maintain the operations and quality of the current sources of cancer-related data such as the statewide tumor registry, the Behavioral Risk Factor Surveillance System, and other key surveillance systems throughout the state.
- 6. Decrease the financial barriers that restrict Iowans' ability to access early detection / cancer screening services through increased knowledge of insurance plan coverage options and other non-traditional payment options for cancer early detection services (including free services).

The existence of this plan and the strong commitment made by *Consortium* members to work in its implementation provides an unprecedented opportunity in Iowa to make significantly more progress to alleviating the burden of cancer on the state than has ever occurred before.

The *Consortium* stands behind this plan and is calling on public officials, other decision-makers, and Iowa's citizens to do likewise. More importantly, the *Consortium* wants people and organizations from all across the state to get involved in its implementation. The *Consortium* as a whole has set some initial priorities and wants others to join in its implementation of these and/or to get more involved in addressing any of the other 44 strategies contained in this 3-year plan.

There is no better time than now to aggressively take on cancer in Iowa and take full advantage of what is already known about how to prevent and cure it. There is no better way to do so than working collectively across the state to make it happen. There is no one better equipped 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.

Introduction

Iowa Consortium for Comprehensive Cancer Control

Changing the Face of Cancer in Iowa: A State Plan for 2003 - 2005

The Face of Cancer in Iowa

Last year, some 14,600 Iowans were told they have cancer. Approximately 6,300 of our fellow citizens lost their lives to this disease. This is just the story for one year. Cancer continues to take a terrible toll on the state, year after year.

When Iowans get cancer, the patient, their family, and their loved ones are changed forever. Important medical decisions must be made. Tough physical, personal, social, and economic consequences have to be anticipated and met head-on. Working, parenting, and social patterns have to be adjusted. When people die prematurely from cancer, Iowa loses forever their talents, experiences, and contributions. Their families and loved ones lose so much more.

Thankfully, research advances have brought us to the point where cancer is no longer the death sentence it once was. More than half the Iowans who get cancer will survive the disease. This means that, each year, the number of cancer survivors in the state continues to grow. This is something Iowa can proudly celebrate.

We have made important gains in the past decade in preventing the disease, detecting it earlier, treating it more effectively, and in beginning to address the many quality of life issues that cancer patients and their loved ones must face. This is another reason for Iowa to celebrate.

But most importantly, Iowa has an opportunity to save many more of our fellow citizens from the consequences of this disease. Using what we already know from science and in working together as individuals, organizations, and communities across the state, Iowans can achieve great, new levels of success in the fight against cancer.

Background

The Iowa Legislature commissioned a report on the burden of cancer in Iowa in 2001. 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*. That report summarizes in detail the available data on cancer in Iowa.

Some of the important findings of the Study Committee include:

- 1 out of 4 deaths in Iowa is caused by cancer, making it the 2nd leading cause of death.
- Every county in the state is affected by cancer.
- More than 65% of cancer occurs in people over the age of 65. Iowa has the 4th largest percentage of people over 65 among the states and that group of people will grow by 57% between now and 2025.
- Racial minorities have some cancers more often and die from some cancers more often than do Caucasians. Most cancer cases in racial minorities in Iowa occur in metropolitan counties.
- Quality of life is increasingly important to those with cancer in their families; yet little is known about the quality of life needs of Iowans and how well they are being met.

Healthy Iowans 2010 written in the late 1990's outlined nine cancer goals for the state. As would be expected, none of these have yet been achieved. Trends show that for seven of the nine goals, progress is being made in the direction of the goal. For the remaining two goals, the trend is moving in the wrong direction. The nine goals and the current status of the trends are:

Healthy Iowans 2010 goals with trends moving in the correct direction:

- All sites mortality
- Lung cancer mortality
- Colorectal cancer mortality
- Breast cancer mortality
- Prostate cancer mortality
- Oropharynx mortality
- Cervix mortality

- Healthy Iowans 2010 goals with trends moving in the wrong direction:
 - All sites incidence
 - Melanoma skin cancer mortality

The Face of Cancer in Iowa also pointed out that Iowa possesses both major assets in the fight against cancer and some significant challenges. Examples of both of these include:

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 underutilized.
- 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 Iowans are getting more obese.

Iowa is clearly burdened by cancer. Many of its citizens and their families are impacted by the disease. Iowa has taken the important step of detailing the burden of this disease in *The Face of Cancer in Iowa* and is making progress in addressing cancer, but much remains to be done. Most importantly, Iowa is well-positioned to fundamentally alter the course of cancer in the state and to relieve its citizens of the many burdens this disease causes. To do so requires concerted, integrated action by many people who are currently working on many different cancer problems. Defining what those actions are and how best to accomplish them together is the next major step in the fight against cancer.

Creating a Comprehensive Statewide Plan

While work was underway on *The Face of Cancer in Iowa* report, the Iowa Department of Public Health submitted a competitive application for funding to the U. S. Centers for Disease Control and Prevention (CDC). Iowa's application was approved for funding and, subsequently, CDC awarded a Comprehensive Cancer Control Planning Grant to the state.

Members of the original Study Committee joined the Department of Public Health and other key cancer leaders from around the state to initiate the development of a strategic comprehensive cancer control plan for Iowa building on the information provided in the *The Face of Cancer in Iowa* report. This resulted in the creation of the *Iowa Consortium for Comprehensive Cancer Control*.

The *Iowa Consortium for Comprehensive Cancer Control*, made up of more than 100 individuals representing 50 agencies and organizations from around the state, has developed this plan as a blueprint for dramatically changing the "face of cancer" in Iowa. The *Consortium* believes there has never been a better opportunity to make the kind of changes that are possible based on this plan. The Consortium invites Iowa's citizens, its leaders, and its many institutions to join in taking the necessary steps to reduce the burden of cancer on Iowa's citizens. This plan shows we know enough to act decisively. Now is the time to act.

Iowa's Comprehensive Cancer Control Plan is organized in the remainder of this document as follows:

VISION - in which the vision for Iowa's comprehensive cancer control effort is articulated.

GOALS - which describe the broad goals for comprehensive cancer control in Iowa.

GUIDING PRINCIPLES - which underlie the identification of cancer control problems and strategies found in the plan.

PRIORITIES FOR CANCER CONTROL - which identify a small number of major cancer control strategies recommended for implementation by the Consortium from among the many strategies found in the plan.

DETAILED GOAL REPORTS - which summarize the key cancer control problems facing the state and outline multiple strategies for addressing them.

CROSSCUTTING STRATEGIES - which outline cancer control strategie that cut across the Iowa goal areas.

THE IOWA CONSORTIUM FOR COMPREHENSIVE CANCER

CONTROL - which describes the role, operations, and accountability of the Consortium in moving from the planning phase to implementation of the plan.

Vision

The Iowa Consortium for Comprehensive Cancer Control Vision:

WORKING TOGETHER TO CONQUER CANCER

GOALS

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

- WHENEVER POSSIBLE, PREVENT CANCER FROM OCCURING.
- WHEN CANCER DOES OCCUR, FIND IT IN ITS EARLIEST STAGES.
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- ASSURE THAT THE QUALITY OF LIFE FOR EVERY CANCER PATIENT IS THE BEST IT CAN BE.
- MOVE RESEARCH FINDINGS MORE QUICKLY INTO PREVENTION AND CONTROL PRACTICES.

The *Consortium* fully supports 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*.

If Iowa works effectively and vigorously to address the goals outlined above, it can expect to see the following general outcomes:

- 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.

GUIDING PRINCIPLES

The following principles guide the development and implementation of the Iowa Comprehensive Cancer Control Plan. The plan 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.

PRIORITIES FOR CANCER CONTROL

During the identification of strategies to address Iowa's major cancer control needs, many ideas surfaced. These were discussed and refined by work groups and appear in the DETAILED REPORTS section that follows for each of Iowa's cancer control goals. Along with each strategy, the cancer control problems they address and the expected outcomes of implementing the strategies are found in the DETAILED REPORTS. The full Consortium then reviewed the top strategies from each goal area and selected a small number to begin implementation work on through 2004. The following six strategies emerged as Iowa's top cancer priorities:

- 1. Develop a statewide information resource (i.e., website) to contain a wide variety of critical cancer-control information (e.g., clinical trials availability, provider locations and contact information, and links to other state and national cancer control information sources). The concept is to centralize information access for both the public and health professionals in order to provide an efficient means for informed decision-making.
- 2. Increase the state excise tax on cigarettes by \$1.00, making the total tax per pack \$1.36.
- 3. Maintain a state commitment to an endowment focused on health issues at levels comparable to that which would have been available prior to the securitization of the tobacco-related Master Settlement Funds.
- 4. Policies should be enacted for all Iowa insurance carriers that specifically prohibit the following actions. The preferred approach for enacting such policies is through voluntary action on the part of insurance carriers themselves. Failing that, legislative and regulatory approaches should be enacted.
 - 1. Requesting or requiring collection or disclosure of genetic information without prior specific written authorization for that particular test from the individual;
 - 2. Using genetic information, or an individual's request for genetic services, to deny or limit any coverage to that individual or their relatives; and
 - 3. Establishing differential rates or premium payments based on genetic information, or an individual's request for genetic services.
 - 4. Releasing genetic information without specific, prior and written authorization by the individual.

Policies should also be enacted for Iowa employers that specifically prohibit the following actions. Again, the preferred approach for enacting such policies should be through voluntary action on the part of employers themselves. Failing that, legislative and regulatory approaches should be enacted.

- 1. Using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits or termination of employment;
- 2. Requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment;
- 3. 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. Releasing genetic information without specific, prior and written authorization by the individual.
- 5. Maintain the operations and quality of the current sources of cancer-related data such as the statewide tumor registry, the Behavioral Risk Factor Surveillance System, and other key surveillance systems throughout the state.
- 6. Decrease the financial barriers that restrict Iowans' ability to access early detection / cancer screening services through increased knowledge of insurance plan coverage options and other non-traditional payment options for cancer early detection services (including free services).

DETAILED REPORTS BY GOAL

This section provides a detailed summary of the cancer control problems identified by the *Consortium's* work groups, the strategies for addressing them, the rationale for the strategies, and expected outcomes of implementing these strategies. It is from these summaries that the priority strategies noted in the previous section are drawn.

As noted previously, the Consortium created guiding principles to help direct the work groups as the various sections of the plan were developed. This resulted in:

- 1. Using scientific data and research to systematically identify priorities and inform decision-making.
- 2. Addressing the full scope of cancer care; primary prevention, early detection, treatment, quality of life, and research.
- 3. Engaging many stakeholders in the creation of the CCC plan, including not only the medical and public health communities but also voluntary agencies, insurers, businesses, survivors, government, academia, and advocates.
- 4. Recognizing the need to coordinate cancer-related programs and activities, thereby creating integrating activities and fostering leadership.
- 5. Recognizing the need to recruit many disciplines administration, basic and applied research, evaluation, health education, program development, public policy, surveillance, clinical services, and health communications to help support and implement the CCC Plan.



WHENEVER POSSIBLE, PREVENT CANCER FROM OCCURING

Priority Strategies

Priority strategies as determined by the full *Consortium* for this goal are the following. Details for each of these priorities are later in this section.

- Increase the state excise tax on cigarettes by \$1.00, making the total tax per pack \$1.36.
- Eliminate the public's exposure to secondhand smoke in workplaces, restaurants, and all other public facilities.
- 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.
- Implement community-based interventions, focusing on children and adolescents by 1) increasing the awareness of sunburn as a risk factor for skin cancer and 2) implementing policy changes to help reduce over exposure to the sun.

Detailed Cancer Problems, Strategies, Rationales, and Outcomes

Cancer Problem #1

Tobacco-related illnesses take the lives of 5,000 Iowans a year and cost the state \$67 million each year. In 1999, approximately 1,660 cancer deaths were directly attributable to tobacco use. Rates of tobacco use among Iowans 18 years and older have remained steady over the past years (current rate of 23.5%, based on data from Iowa's 2002 Adult Tobacco Survey). Although use of tobacco among Iowa youth has significantly dropped between 2000 and 2002, 10.9% of middle school students and 33.7% of high school students report using tobacco products. (2002 Iowa Youth Tobacco Survey)

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

Rationale

It has been estimated by the Centers for Disease Control and Prevention (CDC) that a 10% increase in price reduces consumption by 4 - 8%. During 2002, 18 states increased cigarette excise taxes. Since 1991, Iowa's cigarette excise tax has been \$0.36 per package. In comparison to contiguous states, only South Dakota and Missouri have a lower excise tax.

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

- 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 \$709 million. Of this amount, \$235 million is paid for by the state's Medicaid Program.

Currently, there are more than 50 cessation programs targeting adults and more than 40 programs targeting youth in Iowa. In Fiscal Year 2002, the state's toll-free Quit Line received 2,180 calls. Over the past two years, 2,250 Iowans sought tobacco cessation services from community programs. 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.

Outcomes

- 1. Increased number of calls to Iowa's Quit Line.
- 2. Increased number of Iowans who attempt to quit using 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% of people who are in recovery from alcohol addiction are smokers, compared with 25% of the general public. Smokers in alcohol recovery may be more addicted to nicotine than other smokers. People who have been in treatment for alcohol problems are more

likely to die from tobacco-related diseases than from alcohol-related problems, as they have a higher risk for cancer than recovering alcoholics who do not smoke. 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.

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 that "no person may smoke in a public place or at a public meeting except in designated smoking areas." 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.

- 1. Decreased secondhand smoke health impacts (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 environmental tobacco smoke (ETS), and identify and eliminate the disparities related to tobacco use. 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. Iowa's current level of state funding for tobacco control is approximately \$5 million.

To increase the current budget of the state's Tobacco Use Prevention and Control Program to the minimum level recommended by CDC, funding from an increase in Iowa's cigarette tax could be used. Approximately 6% 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.

- 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 ETS.
- 4. Decreased prevalence of tobacco use among Iowa's diverse populations.

Cancer Problem #2

Obesity increases the risk of some cancers in both men and women. Increasing evidence particularly links obesity to the risk of postmenopausal breast cancer, and also supports increased risk of cancers of the colon, prostate, endometrium, kidney, and esophagus (AICR, 2001).

Compared to other states, obesity is a significant problem in Iowa. There are only 11 states with higher obesity rates than Iowa. Data from the 2001 BRFSS show that almost 23% of Iowans are obese, higher than the national median of 21%. An additional 37% of Iowans are overweight. The percentage of Iowans who are overweight and obese has steadily increased over the past 10 years.

<u>Strategy A:</u> 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.

Rationale

Lighten Up Iowa, a campaign that will be promoted heavily in 2002-2003, has strong statewide backing from government, private and non-profit organizations. Supportive and collaborative activities will help increase Iowans' awareness about the strong link between obesity and cancer.

Outcomes

- 1. Decreased prevalence of overweight/obesity among Iowans.
- 2. Decreased incidence of and mortality associated with cancers linked to obesity.

Strategy B: Enhance the existing state surveillance system to track the prevalence of overweight and obesity among children and youth, grades K - 12, in Iowa.

Rationale

Overweight adolescents have a 70% chance of becoming overweight adults. This risk increases to 80% if one or more parent is overweight. To better understand the prevalence of obesity in Iowa, it is important to have accurate data about the prevalence of obesity among Iowa's youth. Women in Crisis (WIC) data is collected for children through age five. And while there may be local data collected for children and youth in grades K-12, there is no state-level mechanism in place for gathering and analyzing the data.

- 1. Establishment of baseline data that can serve as measurable evaluation indicators for future interventions.
- 2. Development and implementation of interventions which are data-driven.

Cancer Problem #3

Iowa ranks number four in the nation in sunburns. 1999 BRFSS data show nearly 46% of adult Iowans reported experiencing sunburns, with over 71% of the respondents, ages 18-24, 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.

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. Death rates for skin 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.

<u>Strategy B:</u> Implement community-based interventions, focusing on children and adolescents that: 1) increases awareness that sunburn is a risk factor for skin cancer and 2) implements policy changes to help reduce over exposure to the sun.

Rationale

Protection from ultraviolet exposure during childhood and adolescence reduces the risk for skin cancer in adults. Because young people spend a substantial proportion of their lives in school, and some of that time will be spent outdoors, schools need to be sun-safe places to reduce children's exposure to UV radiation. In addition, Iowans of all ages use community facilities such as swimming pools, playgrounds, and outdoor recreational centers, so it is important to provide adequate areas of shade to reduce risk of sunburns.

Outcomes

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

<u>Strategy C:</u> Implement a social marketing campaign to educate Iowa youth regarding the risks associated with excessive exposure to ultraviolet rays from artificial tanning devices.

Rationale

The long-term effects of UV tanning devices are not known; however, these devices have no known health benefits. According to the American Academy of Dermatology, a recent study shows that the UV exposure received from a tanning bed may be just as harmful to the skin as outdoor sun exposure. Therefore, persons who choose to use these tanning devices should be aware of the potential risks and should follow the manufacturer's directions to minimize these risks.

Although there are 1350 registered tanning facilities in Iowa, no data regarding the incidence of burns is collected by local health departments during annual inspections. 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.

- 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 interventions which are data-driven.

Cancer Problem #4

According to the EPA, radon is the second leading cause of lung cancer in the United States today and is responsible for about 14,000 lung cancer deaths in the U.S. annually. 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. IDPH estimates that 72% (or 5 out of 7) of Iowa homes contain radon levels above the recommended action level.

Strategy A: Encourage radon testing of all buildings, before they are sold and at the time of sale, by certified radon measurement specialists.

Rationale

Radon is designated as a Class A carcinogen by the Environmental Protection Agency (EPA). According to the committee on the Biological Effects of Ionizing Radiation (BEIR), exposure to radon accounts for 55% of the radiation dose in a person's lifetime. A recent study completed by the University of Iowa showed that in homes with radon levels measuring 4 piocuries per liter (pCi/L), there was a 50 percent increase in the risk of developing cancer.

The Iowa Radon Control Program (IRCP) currently has one radon program inspector whose primary responsibility is to monitor and inspect the work of the state's 31 licensed mitigation specialists and 43 measurement specialists. Inspections are conducted to assure the requirements of Iowa Code chapters 43 and 44 are met. A complete mitigation inspection, including report preparation, takes approximately two weeks to perform, while a complete measurement inspection, with reports, takes approximately 4 days. Because of the time required and IRCP staff limitations, annual inspections are completed in only about half the cases.

- 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.

<u>Strategy B:</u> Support the programs and activities of the Iowa Air Coalition and IDPH that address mitigation of homes that have tested equal to or above 4 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 any cracks or openings, seepage through pores in concrete, or migration dissolved in water. The EPA recommends that mitigation action be taken to reduce indoor radon levels if a radon test result is 4 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.

<u>Strategy C:</u> Encourage newly constructed homes and buildings to be built according to the 2000 International Residential Building Code, Appendix F.

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., the code contains more than 25 UL Standards for Safety. Currently, 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.

- 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 Institute on Alcohol Abuse and Alcoholism (NIAAA), epidemiological research has shown a dose-dependent association between alcohol consumption and cancer; as alcohol consumption increases, so does the risk of developing certain cancers. However, moderate alcohol use - up to two drinks per day for men and one drink per day for women and the elderly - is not harmful for most adults.

NIAAA estimates that 2 - 4% 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% of esophageal cancers in the United States are attributed to chronic, excessive alcohol consumption and nearly 50% cancers of the mouth, pharynx, and larynx are associated with heavy drinking. Although studies have been conducted, less consistent data link alcohol consumption with cancer of the liver, breast, and colon.

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 2001 BRFSS indicate that 16.2% of Iowans consumed five or more drinks on one occasion in the last 30 days. This percentage is above the national median of 14.8%.

Iowa's 2001 Youth Risk Behavior Survey indicated that 52% of youth in grades 9 - 12 used alcohol during the past 30 days.

Strategy A: Support the goals of Iowa's State Plan for Substance Abuse Prevention, 1999 - 2004.

Rationale

The State Plan for Substance Abuse Prevention, 1999 - 2004 serves as a guide or 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. Increased public awareness regarding the link between alcohol and some cancers.
- 2. Strengthened collaborative efforts for state substance abuse prevention.
- 3. Decreased incidence of cancers related to alcohol consumption.
- 4. Decreased cancer deaths that are alcohol-related.

Strategy B: Promote awareness among primary health care providers about the need to screen all patients for alcohol use/abuse.

Rationale

Preventive health services include early intervention programs that focus on identifying people who are beginning to experience adverse effects caused by excessive alcohol use and who are modifying their drinking patterns. The US Preventive Health Care Services Task Force recommends that providers routinely ask all adults and adolescents to describe their use of alcohol and drugs.

- 1. Increased number of health care providers assessing patients for alcohol use.
- 2. Increased number of Iowans referred to early intervention programs.
- 3. Decreased incidence of cancers related to alcohol consumption.

Cancer Problem #6

Approximately 5-10% of all cases of cancer are "inherited," meaning that a gene predisposing to the development of cancer has been inherited. Individuals who inherit such a gene have an increased risk of developing cancer. If an individual has a genetic alteration associated with cancer predisposition, the chance of developing cancer increases significantly. Early age of onset and multiple primary cancers are common. In some genetic cancer syndromes, such as familial adenomatous polyposis (FAP), DNA testing is considered standard of care to identify atrisk individuals at young ages to initiate screening for colon polyps/cancer at the age of 10 years. Due to the near 100% chance of colon cancer by 40 years, most individuals with FAP will need a prophylactic colectomy once the number of polyps is too great to remove safely during colonoscopy (usually done by the late teens). If an individual is no longer at-risk due to DNA test results, these procedures would not be necessary at such young ages; instead, general population screening recommendations would be pursued, which would save 40 years of surveillance.

Research looking for new genes responsible for cancer predisposition and inherited factors that modify cancer risks is leading to important advances in our ability to gauge the cancer risk of individuals. Comprehensive Cancer Control requires that we take advantage of these advances so we can optimize the best approach to cancer prevention for each Iowan.

<u>Strategy A:</u> Increase availability and use 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. The assessments can be beneficial in identifying high-risk individuals who may benefit from a consultation and/or susceptibility/DNA testing.

Since 1995, the knowledge about inherited cancer predisposition, how to use information from susceptibility/DNA testing in medical management decisions, and how to counsel patients and family members at high risk for

cancer has increased dramatically. 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 markedly, and extraordinary screening and invasive prevention measures would not be necessary.

Outcomes

- 1. Increased number of qualified professionals in Iowa offering cancer risk assessment.
- 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.

Strategy B: Reduce barriers related to susceptibility/DNA testing.

Rationale

Barriers to utilizing susceptibility/DNA testing and consultation include lack of awareness among the general public and lack of knowledge regarding appropriate uses and availability by medical providers. An additional barrier is the fear of discrimination by insurance companies and employers. The cost of susceptibility/DNA tests can also be a barrier as it can be a challenge to obtain prior authorization from insurance companies. Without assistance, most families/providers give up on testing or consultation, as they may be told that it is not a covered benefit and they cannot afford to pay for the service out of pocket.

- 1. Increased number of Iowans undergoing appropriate susceptibility/DNA testing.
- 2. Appropriate use of medical resources for individuals at high risk for cancer.
- 3. Decreased incidence of and mortality from hereditary cancers as a result of increased surveillance and preventive measures.

GOAL 2:

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

Priority Strategies

Priority strategies as determined by the full Consortium for this goal are the following. Details for each of these priorities are later in this section.

- Decrease the financial barriers that restrict Iowans' ability to access early detection cancer screening services through increased knowledge of insurance plan coverage options and other non-traditional payment options (including free services) for cancer early detection services.
- 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.
- Increase primary care provider knowledge and utilization of existing resources for non-traditional, publicly and privately funded payment for early detection cancer screening services.

Detailed Cancer Problems, Strategies, Rationales, and Outcomes

Cancer Problem #1

Most Iowans are not familiar with the screening guidelines for the early detection of cancers. Even if Iowans are knowledgeable about early detection screening guidelines, there is confusion about what services should be performed at what age and at what frequency. Iowans need to understand why early detection is necessary and why they need to take responsibility to participate in screenings.

<u>Strategy A:</u> 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

There is a lack of awareness and confusion among consumers regarding screening guidelines.

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 incidence of cancer detected at later stages. (Initially, incidence will increase but then will decline with continued, regular screenings by consumers.)

<u>Strategy B:</u> 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

The media has a strong influence on how we educate the public about cancer. Misinformation or lack of information can lead to missed opportunities to detect cancer at an early stage.

- 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 incidence 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.

Financial and cultural barriers as well as personal barriers, such as fear and embarrassment, hinder Iowans from obtaining early detection screenings according to recommended guidelines. Many Iowans have 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 the geographic distribution of health care providers trained to perform and interpret early detection screening services 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 measured (e.g., the capacity for colorectal cancer screening through the use of colonoscopy is unknown. There is a reported two- to eight-month waiting period between scheduling and receiving the screening test).

Outcomes

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

<u>Strategy B:</u> Decrease the financial barriers that restrict Iowans' ability to access early detection cancer screening services through increased knowledge of insurance plan coverage options and other non-traditional payment options (including free services) for cancer early detection services.

Rationale

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

Outcomes

- 1. Increased consumer demand for early detection 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 services.
- 4. Decreased number of Iowans citing lack of insurance as a barrier to receiving routine screenings.

<u>Strategy C:</u> Decrease the screening-related barriers of personal fear and embarrassment that Iowans perceive, inhibiting access to routine cancer early detection 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).

- 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 incidence of cancers detected at later stages. (Initially, Incidence will increase but then decline with continued, regular screening by consumers.)

Strategy D: 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, it needs to address these multiple languages and cultural issues that are emerging. Language barriers continue to exist, but there are resources beginning to emerge with respect to cultural barriers (e.g., the National Asian Women's Health Organization's resource guide for cultural barriers).

- 1. Decreased number of Iowans citing language differences and lack of cultural sensitivity as barriers to receiving routine early detection 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 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.

Research indicates that the most important motivator for undergoing screening is a recommendation by a primary care provider. Potential reasons for low cancer screening rates may be partly related to providers who, for various reasons, do not recommend, provide, or facilitate access to screening examinations. Lack of primary care provider advocacy may be due to the absence of economic resources and the inability to perform the screening service.

<u>Strategy A:</u> Enhance the ability of health care providers to recommend or perform 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.

Outcomes

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

<u>Strategy B:</u> 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.

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

Publicly funded entities that provide early detection 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.

Strategy A: Advocate increasing public funding for early detection cancer screenings at entities that provide services at little or no cost to the service recipient.

Rationale

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 services.

- 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 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 incidence of cancers detected at later stages. (Initially, incidence will increase but then decline with continued, regular screenings by consumers.)
- 6. Decreased cancer mortality rates.



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

Priority Strategies

Priority strategies as determined by the full *Consortium* for this goal are the following. Details for each of these priorities are later in this section.

- Develop a statewide website, accessible to both patients and healthcare providers, listing sub-specialists and current clinical trials, eliminating the confusion that comes with searching the internet.
- Utilize cancer support groups, HMO's, insurance carriers, the American Cancer Society, and other organizations for exchanging information among cancer patients, families/caregiver, survivors, and physicians.
- Identify alternative financial options and other resources available for cancer care for uninsured or low-income cancer patients.

Detailed Cancer Problems, Strategies, Rationales, and Outcomes

Cancer Problem #1

Patient Access-Patients across Iowa do not have equal access to cancer care. In particular, the lack of adequate access includes radiation therapy, clinical trials and affordable treatment. Language barriers presented by non-English speaking patients throughout the state affect access to healthcare. In addition, adequate communication skills between healthcare providers and patients, allowing patients to thoroughly understand their disease process and treatment options vary throughout the state.

Strategy A: Identify gaps in treatment options and resources for disenfranchised cancer patients.

Rationale

The barriers (geographic, ethnic, age, language, uninsured/under insured, etc.) of access to care must be identified prior to implementation of other strategies.

- 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: Develop a statewide website, accessible to both patients and healthcare providers, listing sub-specialists and current clinical trials, to eliminate confusion with searching the Internet. (This could be an existing website, formatted to provide links to other websites including the National Cancer Institute (NCI) and University of Iowa Health Care). This will be the same website as listed under Cancer Problem #2, Strategy B.

Rationale

It is confusing to search out cancer-related information on the internet, including locally available clinical trial options and the contact information for sub-specialists across Iowa.

Outcomes

- 1. Increased patient and provider awareness of options available locally (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 healthcare providers.

<u>Strategy C:</u> 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

There is a need for transportation services (to and from treatments and medical appointments) due to a lack of social support, differences in cultural norms, and geographic and financial barriers. The lack of available transportation is a hindrance to obtaining adequate treatment.

Outcomes

1. Increased number of cancer patients able to access treatment services.

Strategy D: Coordinate with local organizations to provide translation services.

Rationale

Health care providers and non-English speaking individuals are unable to effectively communicate about health care needs.

Outcomes

1. Decreased language barriers between cancer patients and health care providers.

<u>Strategy E:</u> Identify alternative financial options and other resources available for cancer care for uninsured or low-income cancer patients.

Rationale

Uninsured or low-income patients do not receive adequate cancer care.

- 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.

Physician Education - Some physicians and other healthcare professionals may be unaware of specific issues unique to the best care of the oncology 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 to facilitate statewide networking and communication among physicians, such as primary care physicians who diagnose 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.

Strategy B: Develop a statewide website, accessible to both healthcare providers and patients, listing sub-specialists and current local clinical trials. (This could be an existing website, formatted to provide links to other websites including the National Cancer Institute (NCI) and University of Iowa Health Care). This will be the same website as listed under Cancer Problem #1, Strategy B.

Rationale

- 1. It is confusing to search out cancer-related information on the Internet, including locally available clinical trial options and the contact information for sub-specialists across Iowa.
- 2. Healthcare providers will have immediate access to information regarding locally available clinical trials and the contact information for sub-specialists across Iowa.

- 1. Healthcare providers will have access to information on when to make referrals and to whom referrals may be made.
- 2. Healthcare providers will be able to obtain information on clinical trials and sub-specialists more easily.
- 3. Increased annual participation in clinical trials.

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, available clinical trials, roles of physicians, advantages and disadvantages of complementary and alternative therapies, and the need for compliance with treatment instructions, especially in self-administered treatment at home.

<u>Strategy A:</u> Utilize cancer support groups, HMO's, insurance carriers, the American Cancer Society, 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 patient needs are met and interaction between physicians and patients will be improved.

<u>Strategy B:</u> Determine current status of non-compliance to prescribed medications among cancer patients for reasons related to cost, unacceptable side effects, and lack of education/understanding relevance to treatment.

Rationale

Non-compliance to prescribed medications may affect therapeutic outcomes and quality of life.

- 1. The degree of non-compliance to drug regimens will be determined.
- 2. The etiology of non-compliance will be determined.

GOAL 4:

ASSURE THE QUALITY OF LIFE OF EVERY CANCER PATIENT IS

THE BEST IT CAN BE.

Preamble: Quality of life should be considered inclusive of diagnosis to end-of-life. It takes into consideration the caregivers as well as the patient. There is currently very little data, research, and scientific fact regarding quality of life issues. As information becomes available, however, it should be analyzed and used to revise and enhance this plan.

Priority Strategies

Priority strategies as determined by the full *Consortium* for this goal are the following. Details for each of these priorities are later in this section.

- Increase health care providers' awareness of quality of life issues and skills to effectively engage their patients in quality of life decision-making.
- Increase patient/family awareness of programs and resources available to address financial needs of the patient and their caregiver/family.
- Improve total physical, emotional, and spiritual well-being.
- The patient care team should take a holistic approach with focused attention to the emotional, physical, spiritual and social well-being and quality of life of the cancer patient in combination with the treatment of their medical condition.

Detailed Cancer Problems, Strategies, Rationales, and Outcomes

Cancer Problem #1

Patients and their caregivers are not optimally involved in defining their quality of life in coordination with their health care providers. Health care providers should actively engage the patient and other health care providers in these discussions.

<u>Strategy A:</u> Increase health care providers' awareness of quality of life issues and skills to effectively engage their patients in quality of life decision-making.

Rationale

The quality of interaction between the patient and health care provider is not consistent or occurring in a widespread manner throughout the state. Often times the wishes of patients and families are not known and respected which results in diminished quality of life. Creating a decision-making partnership early in the treatment process helps the health care provider determine long-term goals that integrate the patient's perceptions/views of quality of life.

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.

<u>Strategy B:</u> 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

The quality of interaction between the patient and health care provider is not consistent or occurring in a widespread manner throughout the state. Often times the wishes of patients and families are not known and respected which results in diminished quality of life. Creating a decision-making partnership early in the treatment process helps the patient determine long-term goals that address the individual's definition of quality of life.

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 healthcare providers.
- 4. Decreased inappropriate decisions made by the patient due to inadequate information.

<u>Strategy C:</u> The patient care team should take a holistic approach with focused attention to the emotional, physical, spiritual and social well-being and quality of life of the cancer patient in combination with the treatment of their medical condition.

Rationale

Often in the treatment of the cancer patient, the physical aspect and treatment of the cancer itself are the focus of the health care provider. It is important to create an atmosphere where all other aspects of life are considered as well.

- 1. Increased number of cancer patients having access to a coordinated treatment team of providers (i.e. physician, nurse, social worker).
- 2. Patient's health, well-being, social interactions will be enhanced (including financial status, dealing with the community, and work circumstances).
- 3. A broader range of professionals will be brought in to supplement the patient care team (e.g., clergy, social workers, massage therapists, financial advisors, and complementary medicine professionals).
- 4. The patient care team will take a holistic approach, focusing attention on the quality of life for the patient in combination with the treatment of their medical condition.

Pain and symptom management are not consistently an integral part of the care plan for cancer patients in Iowa.

Strategy A: Support and further develop the *Pain as a 5th Vital Sign* initiative consistently throughout the state.

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.

There is under-treatment of cancer symptoms, treatment side effects, and life altering problems; this is not consistently recognized and addressed within the medical community. Pain assessment and treatment are not consistent across the state, sending inconsistent messages to patients and providers.

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.

Strategy B: Improve total physical, emotional, and spiritual well-being.

Rationale

Cancer-related symptom assessment and management is not adequate or consistent throughout the state.

Outcomes

1. Cancer care plans will address patients' physical, emotional, and spiritual needs.

<u>Strategy C:</u> Develop a system to identify and support the needs of cancer patients who have completed treatment (i.e., "survivors"), particularly addressing the physical, emotional, and financial outcomes.

Rationale

The impact of cancer does not end with cure and progresses beyond traditional treatment time.

- 1. Cancer survivors will be readily identified and receive support when they desire it.
- 2. Increased awareness on the part of physicians, patients, and caregivers regarding post-treatment, long-term needs of cancer survivors such as concerns of recurrence, body image, sexuality issues, etc.
- 3. Enhanced early intervention to identify needs and develop more effective coping skills that will improve the long term quality of life for cancer survivors.

Current support systems and resources for primary caregivers (i.e. individual who is involved in the day-to-day care of a person with cancer, usually a friend or family member) are not adequate.

Strategy A: Increase awareness of the impact of cancer, and its treatment, on the caregiver.

Rationale

Suffering experienced by primary caregivers, such as family or friends, is an enormous problem that is poorly recognized by healthcare providers, policy makers, the general community, and governmental agencies.

Outcomes

1. Increased caregiver use of programs and resources available to assist them.

Strategy B: Increase patient/family awareness of programs and resources available to address financial 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.

- 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: Educate caregivers on the importance of taking care of themselves.

Rationale

If caregivers do not take care of their own needs, they may not be able to effectively take care of the patient and may develop healthcare needs of their own.

Outcomes

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

GOAL 5:

MOVE RESEARCH MORE QUICKLY INTO PREVENTION AND CONTROL PRACTICES.

Preamble: Cancer medicine is evolving rapidly. Clinical trials are the cornerstone for finding the best treatment, prevention, detection, and cure for cancer. We must strengthen every aspect of the clinical trial process and overcome the many barriers to participation. While 70-80% of pediatric cancer patients participate in clinical trials, currently only 3% of adult cancer patients participate in clinical trials. Even fewer minority and older patients participate. Many trials never accrue a sufficient number of patients and must close. Each closed trial represents a failed opportunity to improve cancer control. It is estimated that at least 10 - 15% of adult cancer patients must participate in trials to move research forward more rapidly.

Factors are present in the State of Iowa that limit the ability of the citizens to participate in clinical cancer trials geared towards cancer therapy or prevention if they so choose. Factors also exist that complicate the performance of cancer population studies, therefore limiting our ability to learn about potential causes of cancer in Iowa.

Iowa needs a dramatic increase in the quality and quantity of clinical trials, and a cultural shift in what research means to the average patient. The system must be financed and organized in such a way that all stakeholders (health care providers, health insurers/third party payers, patients, pharmaceutical companies, and the state government) are invested in the same outcome: finding the best approaches to prevention, diagnosis, treatment, and, ultimately, cure for cancer. Policy changes that facilitate participation in therapy, prevention and population studies by Iowans who wish to participate in such studies would have a positive impact on cancer control across Iowa.

Priority Strategy

The priority strategy as determined by the full *Consortium* for this goal is the following. Details for this priority can be found later in this section.

Policies should be enacted for all Iowa insurance carriers that specifically prohibit the following actions. The preferred approach for enacting such policies is through voluntary action on the part of insurance carriers themselves. Failing that, legislative and regulatory approaches should be enacted.

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

Policies should also be enacted for Iowa employers that specifically prohibit the following actions. Again, the preferred approach for enacting such policies should be through voluntary action on the part of employers themselves. Failing that, legislative and regulatory approaches should be enacted.

- 1. Using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits or termination of employment;
- 2. Requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment;
- 3. 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. Releasing genetic information without specific, prior and written authorization by the individual.

Detailed Cancer Problems, Strategies, Rationale and Outcomes

Cancer Problem #1

Significant financial barriers exist to participation in clinical trials.

There is a lack of clarity related to coverage of clinical cancer trials in the policies of many insurance carriers. The experience of many cancer patients and physicians indicates the willingness of carriers to cover the standard medical care that accompanies participation in clinical trials is inconsistent. This lack of clarity and lack of consistency limits the willingness of subjects to participate in therapeutic, prevention and population trials. Concern among potential clinical trial subjects that there is a lack of support for standard medical care from insurance carriers resulting from participation in clinical cancer trials limits the willingness of those potential research subjects to participate in such clinical trials.

Relevant Background: In June 2000, a Federal Executive Memorandum was issued requiring Medicare to reimburse all routine patient care costs for participation in clinical trials. While this action will significantly increase access for some to clinical trials, there are still financial barriers for Medicaid recipients, those covered by private health insurance or other third party payers, and those without health insurance. Currently, most research trials cover the cost of the investigational part of the trial, but participants often face significant expenses for physician and hospital fees and laboratory tests. Insurance programs and third party payers often refuse coverage for treatments, diagnostic procedures, and prevention initiatives under investigation. as well as any additional costs related to the trial. Thus, individuals participating in trials are sometimes required to pay out-of-pocket health care costs, which discourage participation. Ensuring that routine patient care costs will be covered by health insurance is the first step in encouraging greater participation in clinical trials.

<u>Strategy A:</u> Gather and make public information from various insurance carriers related to support through insurance plans for clinical cancer trial participation and whether or not they cover costs of routine patient care when enrolled in a clinical cancer trial.

Rationale

Make available and readily accessible to the public all information about the Iowa insurance carriers' willingness or unwillingness to pay for routine patient care costs for participation in clinical cancer trials. Thus, individuals and corporations selecting insurance carriers will be aware of the potential of being excluded from a clinical cancer trial testing newer and better approach to prevention, detection and treatment.

Outcomes

1. Development of a central database that outlines support (or lack of support) from insurance carriers that describes their policies related to payment of routine medical care costs that occur as part of participation in clinical cancer trials.

<u>Strategy B:</u> Distribute information related to clinical cancer trials to insurance carriers, including the importance and value of well-designed clinical cancer trials, and encourage them to develop policies that specifically emphasize that routine patient care costs resulting from clinical cancer trials will be covered as outlined for Medicare (see http://cis.nci.nih.gov/fact/8_14.htm).

Rationale

Develop a consistent approach across the state to supplying coverage for clinical cancer trials that will facilitate the ability of willing subjects to participate in clinical trials. No one should be excluded from research trials because they cannot afford the standard patient care costs associated with a trial.

Outcomes

1. Issues related to insurance coverage for clinical trials will be consistent, whether payment is coming from the government via Medicare or Medicaid, or from a private insurance carrier.

The potential for genetic discrimination is an obstacle to participation in clinical cancer trials.

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 have a negative impact on the current or future insurability of the subject, or, if an inherited factor is identified, on the insurability or employability of family members in health insurance, life insurance and employment. This limits participation in important and promising approaches to cancer prevention, screening and treatment.

Relevant Background: It is important to encourage the use of genetic information, where appropriate, to help determine the best prevention, early detection and treatment options for people at high-risk for or with cancer, and to foster continuing research using genetic information to find the causes of cancer and a cure for it. By doing so, patients receive the full benefit that modern, scientifically proven technology can bring to bear on reducing the burden of cancer. To encourage widespread use of genetic technologies, protections must be in place that safeguard individuals from the misuse of their genetic information. Genetic information is uniquely private and should not be disclosed without authorization by the individual. Improper disclosure can lead to significant harm, including discrimination in the areas of employment, health care and insurance. The fear of potential discrimination threatens both a patient's decision to use new genetic technologies and to seek the best medical care from a physician. Many Iowa insurance carriers and employers lack a clear understanding and/or clear policies related to genetic discrimination.

Strategy A: Policies should be enacted for all Iowa insurance carriers that specifically prohibit the following actions. The preferred approach for enacting such policies is through voluntary action on the part of insurance carriers themselves. Failing that, legislative and regulatory approaches should be enacted.

1. Requesting or requiring collection or disclosure of genetic information without prior specific written authorization for that particular test from the individual;

- 2. Using genetic information, or an individual's request for genetic services, to deny or limit any coverage to that individual or their relatives; and
- 3. Establishing differential rates or premium payments based on genetic information, or an individual's request for genetic services.
- 4. Releasing genetic information without specific, prior and written authorization by the individual.

Policies should also be enacted for Iowa employers that specifically prohibit the following actions. Again, the preferred approach for enacting such policies should be through voluntary action on the part of employers themselves. Failing that, legislative and regulatory approaches should be enacted.

- 1. Using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits or termination of employment;
- 2. Requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment;
- 3. 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. Releasing genetic information without specific, prior and written authorization by the individual.

Rationale

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

- 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 impact insurability.
- 2. Increased participation in clinical trials that involve genetic testing.

Strategy B: Ask the State Legislature to pass legislation that prohibits genetic discrimination in life insurance, health insurance or employment, and protects those discriminated against with meaningful enforcement.

Rationale

Initiating a legislative process would encourage insurance carriers to pay attention to the issue of genetic discrimination and, if voluntary approaches are not successful, could lead to actual legislation.

Outcomes

1. Nondiscrimination legislation with strong enforcement mechanisms that include a right to sue would decrease concern on the part of potential clinical trials subjects related to whether results obtained as part of the research program could impact insurability. This would alleviate Iowans' concerns related to genetic analysis and insurability.

There is a need to provide adequate education and counseling to patients interested in clinical trial participation.

Strategy A: Produce a handbook and video for Iowa citizens recently diagnosed with cancer. The handbook would provide basic, factual information in a low literacy format. The booklet would be used to supply an overview or as an introduction before reading more comprehensive materials. The companion video would include personal messages from Iowa physicians/providers and patients who have participated in clinical trials. Both products would be distributed free of charge to patients and providers in Iowa.

Rationale

The handbook and video would be used as the basis for developing a comprehensive tool to facilitate doctor-patient communication in the clinic and hospital setting. Physicians and nurses could use this tool when discussing Clinical trial participation with patients. An educational workshop for health care providers, using the book and video, could assist providers in reaching minority patients in a culturally relevant, literacy appropriate manner.

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.

Strategy B: Develop an interactive, multimedia, computerized decision support system (CDSS) on clinical cancer trials for low-literate, multiethnic Iowans who speak English, Spanish, or Serbo-Croatian. The CDSS should be culturally and linguistically sensitive. The CDSS should educate and inform through multimedia approaches (e.g., voice-over narrative in simple English, Spanish, or Serbo-Croatian; use of photo novella and/or "soap opera" presentation of situational material that allows patients to explore possible consequences associated with different decisions).

Information about clinical trial availability and access is not uniform. Information related to clinical trials across Iowa is not readily available to patients and their health professionals interested in learning more.

Strategy A: Develop a central site, preferably a website, that is updated regularly and includes information about open clinical trials across the State of Iowa, as well as information about who to contact concerning additional information and potential eligibility.

Rationale

Establish a single site for distribution of information related to clinical cancer trials.

Outcomes

1. Information related to clinical trials will be readily available to both physicians and patients.

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 so as to optimize the opportunities for integration and resource management and also 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
- 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 a listing of the goal-oriented strategies (abbreviated) for consideration during implementation (including some options for combining them) and any new strategies identified.

Advocacy

These strategies include both legislation and also voluntary policy development.

- Maintain a state commitment to a health focus endowment at levels comparable to that which would have been available prior to the securitization of the tobacco-related Master Settlement Funds.
- Increase the state excise tax on tobacco products.
- Eliminate public exposure to secondhand smoke.
- Increase funding for a comprehensive tobacco prevention program.

- Make policy changes to reduce harmful sun exposure among children and adolescents.
- Increase public funding for cancer early detection.
- Designate pain as a 5th vital sign.
- 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.
- 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 general awareness of cancer screening and early detection guidelines.
- Increase patient/caregiver awareness of cooperative decision-making.
- Increase awareness of resources to support patients, families and caregivers.
- Increase awareness level of cancer patients regarding clinical trials and about the coverage by individual health insurance coverage by carriers for clinical trial participation.

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.
- Develop professional education programs on clinical trials participation and linkages.
- Incorporate tobacco use cessation into the programs of licensed substance abuse treatment agencies.

- Provide and promote education among primary health care providers on: early detection and screening, tobacco use cessation, alcohol use, quality of life issues, treatment options, clinical trials, pain management, and palliative care.
- Educate health care providers on their roles in educating patients and family members about the topics noted in the bullet above.
- Develop and maintain a centralized cancer information resource for health professionals.
- Develop a comprehensive program for improving patient and provider communications.

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.
- Develop an approach convincing insurance providers of the relevance of clinical trials and to voluntarily provide coverage.
- Increase funding for a comprehensive tobacco prevention program.
- Develop a system for identifying the financial and other support needs of cancer patients who have completed treatment.
- Provide resources for and promote public awareness of available cancer early detection and screening services.
- Identify and promote resources to fund cancer treatment options and reduce financial barriers to treatment.
- 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.

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/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.
- Determine non-compliance rates to prescribed medication and the reasons for them.
- Develop a system to identify the needs of cancer patients who have completed treatment.
- Gather information from health insurance providers on coverage for clinical trials participation.

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 such as geography, age, racial, ethnic and cultural backgrounds, and socioeconomic differences. 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.

Web-Based Information Resource(s)

There are several strategies that 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* believes strongly that, to the extent possible, these various proposals should be implemented through a single web portal. In addition, existing cancer-related website resources in Iowa should be considered as a "home" for such resources before considering the development of a completely new resource.

IMPLEMENTATION

A group of Iowans concerned about cancer came together in 2001 to begin working on *The Face of Cancer in Iowa*, the legislatively mandated report that details the burden of cancer on the people of Iowa. A broader group of Iowans, including health professionals, researchers and representatives of many state and community organizations concerned about cancer worked together through 2002 and into 2003 to produce this plan in response to the burden issues described in *The Face of Cancer in Iowa*. In all, more than 100 individuals from 50 agencies and organizations and communities across the state volunteered their time to complete this plan. It is their expressed desire to see the plan implemented and a concerted, statewide effort aggressively undertaken to significantly reduce the burden of cancer on Iowa's citizens.

To assure implementation of this plan, it is recognized that a joint effort of many organizations representing the private, government and not-for-profit sectors of Iowa must work together. The participants in the planning process believe that successful implementation of the plan will require 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 implementing 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.
- 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 self-proclaimed *Iowa Consortium for Comprehensive Cancer Control* whose initial 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.

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.

Seven implementation groups and three standing committees have been formed. Priorities determined by the full *Consortium* have been combined and assigned to these entities.

For the time being, the structure of the *Consortium* will remain informal and as described above. It is recognized that as the *Consortium* grows and becomes more actively engaged in implementation, it will need to adjust its structure and eventually develop more formal policies and procedures for its operations.

Assuring Accountability

There are two primary mechanisms for assuring accountability for the 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 groups. The seven 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.

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 announcing 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 current status of the cancer burden on 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. In addition, an intra-agency agreement has been signed with the University of Northern Iowa to conduct an evaluation of progress. In collaboration with staff from the University of Iowa, an evaluation plan has been developed. After the evaluation is conducted, it is anticipated the results will:

- · Describe current implementation professes and characteristics of key staff and partners.
- · Describe lessons about barriers and successes to plan implementation.
- · Present key finding that can by used by the Iowa Cancer Consortium to forge recommendations.

This plan, from its inception, has been viewed as a 'living' document by the *Consortium*. The plan outlines a broad vision and goals and identifies priority strategies for implementation in fiscal year 2003 - 2004. 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.

Our thanks to the following Iowa Consortium Comprehensive Cancer Control members:

Maleka Ahmed, MD Iowa Medical Society

Theresa Allen American Cancer Society Midwest Division, Inc

Dianne Anderson Iowa State University Center for Survey Statistics and Methodology

Lavern Bird The Finley Hospital Wendt Regional Cancer Center

Bobbie Bohnsack Iowa Department of Public Health Tobacco Use Prevention & Control

Ed Bottei, MD Iowa Statewide Poison Control Center

Mary Ellen Carano, RN, MSW Leukemia & Lymphoma Society

Christine Carpenter Iowa Breast Cancer Edu-action

Jolene Carver, MSN, RN Iowa Department of Public Healt Bureau of Cancer Prevention and Control

Martha Cline American Lung Association of Iowa

Jane Condon, RN, BSN, MBA Calhoun County Health Department

Marcia Coughennower, RN, CGRN Midwest Regional Society of Gastroenterology Nurses and Associates

Libby Coyte, PA Broadlawns Medical Center

Janice Edmunds Wells Iowa Department of Public Health Minority Health Advisory Board

Vickie Evans, RN, C.P.H.Q. Wellmark BCBS of Iowa

Paul Fee, MD Hospice of Siouxland

Cindy Fiester, BA Healthy Linn Care Network

Marvin Firch Iowa Department of Public Health Bureau of Health Care Access

Kathleen Fleming Iowa Parish Nurse Network

Ro Foege Iowa House of Representatives

Doug Getter Iowa Biotechnology Association

Lori Glade Hospice of Siouxland Mark Goedken Hospice of Siouxland

Lorrie Graaf, RN Centers for Disease Control & Prevention

Mary Beth Gross, Pharm D Iowa Pharmacy Association

Hayley Harvey, DDS, MS Broadlawns Medical Center Oral Medicine

Lori Hilgerson, MPH, CHES Iowa Foundation for Medical Care

Uta Hoehn John Deere Health Care

Jude Igbokwe, PhD Iowa Department of Public Health Center for Health Statistics

Dennis Janssen Iowa Department of Human Services Bureau of Managed Care and Clinical Services

Laurie Jensen-Wunder American Cancer Society Midwest Division, Inc

Kerry Juhl Wellness Council of Central Iowa

Susan Kell, RN Iowa Academy of Family Physicians

Linn Kinseth Mercy Cancer Center

Becky Kresowik Iowa Foundation for Medical Care

Joy Larsen Haidle, MS, CGC University of Iowa Division of Genetics

Amber Leed-Kelly, MA, CHES Alegent Health Immanuel Medical Center

Kristine Leeper Iowa Pain Management Clinic

Louise Lex, PhD Iowa Department of Public Health Healthy Iowans 2010

Mary Loots, RN, OCN, CRA Iowa Oncology Research Association

John Lowe, Dr.Ph, FAHPA, FAAHB University of Iowa College of Public Health

Charles Lynch, MD, PhD University of Iowa Iowa Cancer Registry

Ame Lyons, RN Planned Parenthood of Southeast Iowa Kelly Manahan, MD University of Iowa Division of Gynecologic Oncology

Kelly Marshall Pharmacia Corp. & PHARMA in Iowa

Judy McFarlin Genesis Cancer Program

Gail Meyer Iowa Hospital Association Nursing & Patient Services

Mary Murphy Iowa Health System, John Stoddard Cancer Center

Pat Murphy Iowa House of Representatives

Jill Myers Geadelmann, BS, RN Iowa Department of Public Health Cancer Prevention and Control Bureau

Ron Nielsen American Cancer Society Volunteer

Lois Noring American Cancer Society Volunteer

Lori Obluck American Cancer Society Midwest Division, Inc

Pat Ouverson, RN American Cancer Society Midwest Division, Inc

Don Owens, MA Iowa Department of Public Health Division of Tobacco Use Prevention and Control

Karen Packer Marshalltown Cancer Support Group

Heidi Petersen, RD, LD Iowa Nutrition Education Network

Ken Petersen American Cancer Society Volunteer

Margaret Richey Iowa Nebraska Primary Care Association

Joy Rueber Iowa Department of Public Health

Kathleen Schneider, PhD Des Moines University Public Health Program

Sarai Schnucker Beck, Reverend Ecumenical Ministries of Iowa

Sheri Schroeder, PA Broadlawns Medical Center

Sue Scoles, RN, BSN Mary Greeley Medical Center William R. Bliss Cancer Center Wendy Sontag, LISW Leukemia & Lymphoma Society

Lisa Stephens National Cancer Institute Cancer Information Service, North Central Region

Carolyn Sullivan, RN Iowa Hospice Organization

Robert Summers, MD University of Iowa Hospitals & Clinics Department of Internal Medicine

Sarah Swisher Oncology Nurses Society

Robin Thompson, MHA University of Iowa Hospitals & Clinics Department of Internal Medicine

Jodi Tomlonovic, MPA Family Planning Council of Iowa

Tanya Uden-Holman, PhD Iowa Partnership for Quality Care in Dying with Dignity

Lisa Van Allen, PhD, CET Healthy Linn Care Network

Norm Van Klompenburg Commission on Substance Abuse

Catherine Vance, RN, PhD Iowa Department of Education

Molly Veenstra, RN, BSN Susan G. Komen Breast Cancer Foundation

Stephen Vincent, DDS, MS University of Iowa College of Dentistry

Ginny Wangerin Des Moines Area Community College Nursing Education

Ray Webster, MD, MPH Principal Financial Group

George Weiner, MD Holden Comprehensive Cancer Center

Michelle West, PhD University of Iowa State Health Registry

Karla Wysocki American Cancer Society Midwest Division, Inc

Ted Yank Holden Comprehensive Cancer Center

Janet Zwick Iowa Department of Public Health Division of Health Promotion, Prevention, and Addictive Behaviors