



Prostate Cancer Control Plan for Michigan
(Updated 2005)

From the Advisory Committee on Prostate Cancer

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Executive Summary

Introduction

The Michigan Cancer Consortium (MCC) Advisory Committee on Prostate Cancer (ACPC) was convened in 2004 to review and revise the 1998 Prostate Cancer Control Plan for Michigan. A panel of prostate cancer experts and advocates assessed progress made since 1998, the current state of the science, and the experience of the panel's members to develop recommendations to guide the Michigan Department of Community Health and the MCC for the next five years. The Committee formed three workgroups to focus on 1) primary and secondary prevention, 2) treatment, and 3) survivorship issues. Crosscutting issues of epidemiology, accessibility, disparities, and genetics were also considered. A goal was identified for each of the three focus areas accompanied by specific measurable objectives and strategies to achieve the desired outcomes.

Burden of Prostate Cancer in Michigan—Why this is an important disease to address

Prostate cancer is the second leading cause of deaths due to cancer in Michigan men. About 14% of Michigan men will be diagnosed with prostate cancer sometime during their lives; about 3 % of Michigan males overall will die of this disease, the number is about 5% for black men. In 2002, there were 8,676 new cases of prostate cancer in Michigan (age-adjusted incidence rate of 195.0 per 100,000 men). There were 985 deaths from prostate cancer in Michigan in 2003 (age-adjusted mortality rate of 25.5 per 100,000 men). At this time, there are approximately 80,000 prostate cancer survivors in Michigan. There is a disproportionate burden of prostate cancer in African American men who have an incidence rate of prostate cancer 1.4 times that of Whites and a disease specific mortality rate about 2 times that of Whites.

Prostate Cancer Control Recommendations

1) Prostate Cancer Primary and Secondary Prevention Goal

Increase by 2010 awareness of prostate cancer risk factors as well as the benefits and risks of prostate cancer screening among primary care physicians, high-risk men, and the general public.

Objectives

- By 2010, there will be a 30% increase in knowledge of the 2006 Michigan Cancer Consortium prostate cancer early detection recommendations among primary care physicians (Baseline 1995 KAP surveys), the public, and high-risk populations (Baseline 1995 KAP surveys; SCBRFSS 2001-02).
- By 2010, increase from 70% to 80% the awareness of prostate cancer risk factors among African American men.
- By 2010, there will be a 30% increase in adherence to the 2005 Michigan Cancer Consortium Prostate Cancer Early Detection Recommendations* among primary care physicians, with particular emphasis on populations of higher than average prostate cancer risk.

***Updated Prostate Cancer Early Detection Recommendations**

Men who MAY be candidates for early detection

- Early detection beginning at age 50 may be appropriate for men who have a life expectancy of at least 10 years.
- Higher risk men may be candidates for early detection starting at age 45. Men at higher risk are African Americans, men with a family history of prostate cancer, and men in Hereditary Prostate Cancer families, including BRCA1 and BRCA2 mutation carriers.

All candidates for early detection should be fully informed of the potential risks and benefits of early detection before being tested

- Individual counseling by a health professional
- Access to the CDC decision aids *Prostate Cancer Screening A Decision Guide* or *Prostate Cancer Screening A Decision Guide for African Americans* available free of charge at www.cdc.gov/cancer/publica.htm#printed or to another high quality decision aid

Health Care Providers should then

- Address any patient concerns
- Facilitate a shared decision making process on early detection for prostate cancer
- If the man chooses to be tested, both a PSA and a DRE should be done.

When an early detection test or biopsy results are indicative of prostate cancer, refer men to the MCC decision aid *Making the Choice: Deciding What To Do About Early Stage Prostate Cancer* available free of charge in English, Spanish, and Arabic at www.prostatecancerdecision.org or by calling 800-249-0314.

2) Prostate Cancer Treatment Goal

By 2012, a higher proportion of men with localized/regional stage prostate cancer on Watchful Waiting, and men with advanced or recurrent prostate cancer will receive appropriate surveillance and/or active treatment including increased enrollment in clinical trials.

Objectives

- By 2012, the proportion of men with localized/regional stage prostate cancer on Watchful Waiting who are not receiving cancer specific follow up will be measured through the use of surveys and/or cancer registries.

Based on these findings, develop means to improve the proportion of men with localized/regional stage prostate cancer on Watchful Waiting who receive cancer specific follow up care.

- By 2012, the proportion of men diagnosed with advanced or recurrent prostate cancer that receive active treatment and/or are enrolled in clinical trials will be measured through the use of surveys and/or cancer registries.

Based on these findings, develop means to improve the proportion of men diagnosed with advanced or recurrent prostate cancer who receive active treatment and/or are enrolled in clinical trials.

3) Prostate Cancer Survivorship Goal

By 2010, practice guidelines and educational materials will be available for professionals and survivors/families that address prostate cancer symptom management across the survivor continuum to decrease morbidity.

Objective

- By 2010, develop and distribute practice guidelines for prostate cancer symptom management to Michigan primary care providers and pertinent specialists.
- By 2010, provide educational materials for prostate cancer symptom management to prostate cancer survivors and their families that are culturally sensitive and at an appropriate reading level.

Recommendation to the MCC

After thoughtful study, deliberation, and discussion, the survivorship goal and objectives were recommended to be the next prostate cancer priority for focused collaborative action by the MCC and its member organizations.

Introduction:

Development of the Recommendations

The Prostate Cancer Control Plan for Michigan (Updated 2005) is an important component of the Michigan Cancer Consortium's (MCC's) Comprehensive Cancer Plan for 2005-2010. The recommendations contain what Michigan prostate cancer experts believe are the most important actions that can be undertaken to address prostate cancer issues in the state of Michigan. While many of these recommendations focus on provider, public, and patient education and on morbidity rather than directly addressing mortality, the ultimate goal is always to reduce mortality as well as morbidity; by implementing this plan, mortality will be reduced, albeit indirectly.

In 1996 the MCC and MDCH asked its panel of experts that made up the Advisory Committee to develop recommendations for prostate cancer control with specific goals, objectives, and strategic activities designed to reduce mortality and morbidity. Many projects have been undertaken in the past seven years based on the 1998 Prostate Cancer Control Plan, and the MCC decided it was time to reassess the plan and determine the need for new direction. The MCC's Advisory Committee on Prostate Cancer (ACPC) was reconvened in 2004 to review and revise the 1998 Prostate Cancer Control Plan for Michigan and to advise the Michigan Department of Community Health (MDCH) on issues related to prostate cancer control. With the publication of this document, the original Prostate Cancer Control Plan has now been updated. A panel of prostate cancer experts and advocates assessed progress made since 1998, the current state of the science, and the experience of the panel's members to develop recommendations to guide the Michigan Cancer Consortium and the Department of Community Health for the next several years.

The ACPC was composed of experts and advocates who represented the full spectrum of Michigan institutions, agencies, and disciplines concerned with prostate cancer. Members included physicians from various specialties, nurses and other health care providers, teachers and research scientists, representatives of hospitals and other health care settings such as universities, public health entities, and professional organizations, and survivors. The ACPC was co-chaired by Raymond Demers, MD, MPH, CEO and Medical Director of the Great Lakes Cancer Institute, and David Wood, MD, Professor of Urology, University of Michigan,

Based upon a review of the relevant data and the collective experience of the group, the Committee formed three workgroups to focus on primary and secondary prevention, treatment, and survivorship. They also considered issues related to epidemiology, economics, disparities, and genetics. Priorities were identified for each of the three focus areas accompanied by specific measurable objectives and strategies to achieve the desired outcomes. The ACPC met on September 19, 2005 to review and discuss reports from each of the workgroups and to formulate final recommendations. After thoughtful study, deliberation, and discussion, the ACPC unanimously recommended that the survivorship goal and objectives be the next prostate cancer priority for focused collaborative action by the MCC and its member organizations. The Plan was presented to the MCC Board in February 2006.

Activities and Achievements, 1998-2005

The Prostate Cancer Action Committee (PCAC) was convened in 1998 to address the priority. The PCAC has undertaken several related projects to implement the initial MCC prostate cancer priority:

By 2006, prostate cancer patients will have their knowledge and understanding of prostate cancer, treatment options, side effects, and quality-of-life issues measured by patient surveys, with findings used to develop, disseminate, and evaluate new patient education materials.

Surveys conducted to evaluate the knowledge of patients newly diagnosed with prostate cancer in Michigan determined that many men lack knowledge of treatment alternatives (only 62% knew standard treatment options) and of side effects. White men reported higher rates of knowing their Prostate Specific Antigen (PSA) result, stage and grade (92%, 93% and 99% respectively) than African American men (69%, 88% and 85% respectively). Ninety-five percent of all men wished to participate in their treatment decisions.¹

A critical review of existing patient education materials (PEMs) available from major cancer education organizations was then performed. In this review, it was noted that most patient education materials did not describe all of the standard treatment options. The 42 PEMs that did describe alternatives were largely found to be accurate, but insufficient to support informed decision-making.²

These findings suggested the need for more effective PEMs. The PCAC developed new patient education materials in booklet, audiotape, and web versions, which include quantitative comparisons of side effects from treatment options, and are unique in addressing a broad audience, including low literacy men. Complex medical information has been “translated” for a low literacy audience. This PEM is titled *Making the Choice: Deciding What to Do About Early Stage Prostate Cancer*.

Focus groups were conducted with men newly diagnosed with prostate cancer to assure that the booklet was non-biased and was a low literacy tool with utility in this population. The evaluation found the materials to be clear and useful in reaching a treatment decision. Newly diagnosed patients reported more discussions with doctors about treatment options, and showed increases in knowledge of side effects of radiation therapy. The plain language materials presenting medical evidence in text and numerical formats appeared acceptable and useful in decision-making about localized prostate cancer treatment.³

¹ Wei, J.T., Dunn, R., Sanda, M., Hembroff, L., Taub, D., Demers, R., Tiwari, A. Survey of men newly diagnosed with localized prostate cancer: implications for patient education. *J Urol* 2003, 169: 14.

² Fagerlin, A., Rovner, D., Stableford, S., Jentoft, C., Wei, J.T., Holmes-Rovner, M. Patient education materials about the treatment of early-stage prostate cancer: a critical review. *Ann Intern Med* 2004, 140: 721-728.

³ Holmes-Rovner, M., Stableford, S., Fagerlin, A., Wei, J.T., Dunn, R.L., Ohene-Frempong, J., Kelly-Blake, K., Rovner, D.R. Evidence-based patient choice: a prostate cancer decision aid in plain language. *BMC Medical Informatics and Decision Making* 2005;5:16-27.

The website for the online format of the product was activated in August 2003. Distribution of the booklet and audio set began in November 2003. The materials have been well received as demonstrated by the orders for the booklet and audio set and the website statistics that include users from 46 states, Canada, Pakistan, Holland, the U.K., and Ghana in addition to Michigan individuals and organizations. To maintain its evidence-based status, the content of the text has been updated in December 2004 and in October 2005. A statewide dissemination plan is currently being developed.

In addition to implementing a MCC Initiative priority, these projects fostered an intensely collaborative effort among Michigan State University, the University of Michigan, Wayne State University, and the Henry Ford Hospital System. This collaboration is in itself a remarkable achievement, consistent with the mission of the MCC to be a “forum for collaboration to reduce the burden of cancer among the citizens of Michigan.”

In addition to the implementation of the prostate cancer priority, other prostate cancer activities have included the following:

1) The Cancer Burden in Michigan: Selected Statistics

The MPHI Cancer Epidemiology and Program Evaluation team develops this report in support of the MCCI on a regular basis, now yearly; the most recent edition is December 2005. The data from this report is the basis for much of the decision making on priorities for prostate cancer work. The most recent data on prostate cancer is summarized in the section “The Burden of Prostate Cancer in Michigan” and presented in detail in Appendices E and F and at www.michigancancer.org/Resources/SpecialMCCReports.cfm.

This report describes the cancer burden in Michigan in terms of morbidity and mortality, and the human and financial cost associated with five cancer sites: breast, cervical, colorectal, lung and prostate. Data are from the Michigan Resident Death Files and from the Michigan Resident Cancer Incidence File, which are provided by the MDCH, Division of Vital Records and Health Statistics. Michigan rates are compared with national mortality and incidence rates from the SEER Cancer Statistics Review. Also presented are data on the stage at diagnosis for cases reported in Michigan.

A summary of data on cancer-related behavioral risk factors were obtained from MDCH’s Behavioral Risk Factor Survey System (BRFSS), the Michigan State Board of Education’s Michigan Youth Risk Behavior Survey (YRBS), and the Special Cancer Behavioral Risk Factor Survey (SCBRFS) from MDCH and MPHI. In addition, analyses of years of life lost due to the selected cancers are presented as well as analyses of some of the financial costs of cancer.

2) The Prostate Health Awareness (PHA) Curriculum

This community presentation was developed by researchers at the Karmanos Cancer Institute (KCI) and Wayne State University. Because of the disparate burden of prostate cancer on African Americans, the main target audience of the initial program was the African American community of Detroit. The program has been presented to African American and other ethnic groups through the KCI Community Education Department. Over the past three years, the PHA Curriculum has been adapted to be culturally competent to the Hispanic community of Michigan

and then translated into Spanish with the addition of information on local community resources. Currently, focus group testing is being done on the Spanish version. In the next year, methodologies to make this resource available throughout Michigan will be developed and then implemented.

3) Basic Pathology Lexicon Project

In 2003, a committee was established to address the inconsistencies and variations in cancer pathology reporting practices throughout Michigan and to develop a standardized pathology Lexicon and reporting format to assist with treatment decisions and to provide health care policy makers and analysts with accurate data to determine the cost-effectiveness of various health care measures. This work was initially limited to prostate cancer and colorectal cancer; however, through information obtained in regional meetings and from the MCC Board, a decision was made to expand the pathology lexicons to include all common cancer sites. This expansion of scope was primarily based on the assertion that pathologists are more likely to adopt the lexicon for prostate cancer (and other specific cancers) if the lexicon for the particular cancer is embedded in a more comprehensive process than dealing with a single cancer site.

Through the dedication of the Basic Lexicon Committee and the collaborative efforts of the various MCC partner organizations, much has been accomplished over the past few years. Baseline data on reporting practices for breast, colorectal and prostate cancer specimens were obtained from facilities that reported more than 250 cancer cases annually. A consensus was reached on the data elements to include in a standardized template. A draft template was developed for dissemination and pilot use among various facilities throughout the state. Regional meetings were held to educate professionals on the importance of the project, to recruit pathologists to participate in the pilot phase and to initiate a forum for further discussion. To enhance the information obtained in the pilot phase and to contribute to the evaluation of this project, a survey was developed to collect data regarding the usability of the template in actual practice settings and to assess the likelihood of users adopting this type of reporting format into their facility. The Lexicon Synoptic Templates that were drafted and pilot tested by the Lexicon Advisory Committee were approved by the MCC at the September 21st, 2005 MCC Board meeting. The Lexicon templates, which include most cancer sites, are now posted and available for download on the MCC website at: www.michigancancer.org/OurPriorities/StandardizedLexicons_InformationForProviders.cfm

The Burden of Prostate Cancer in Michigan

About 14 percent of Michigan males will be diagnosed with prostate cancer sometime during their lives, and about 3 percent of Michigan males will die of this disease. In 2002, there were 8,676 new cases of prostate cancer in Michigan. The age-adjusted incidence rate in Michigan was 195.0 per 100,000 men (171.8 for white men, and 297.2 for black men). There were 985 deaths from prostate cancer in Michigan in 2003. The age-adjusted mortality rate was 25.5 (23.6 for whites and 44.7 for blacks).

There was a sharp increase in incidence rates from 1988 to 1992 associated with the increased use of screening with the prostate-specific antigen (PSA) test. This resulted in cases being diagnosed earlier and a decrease in the proportion of cases diagnosed at the distant stage. The most likely explanation is that cases that would have been diagnosed later had their diagnosis date moved forward (lead time bias). The impact on survival remains to be established. According to the 1995-2000 results of the federally funded Surveillance, Epidemiology, and End Results (SEER) program, the five-year relative survival rates for prostate cancer were 100 percent for whites and 96 percent for blacks.

Death rates fluctuated between a low of 24.1 per 100,000 population in 1985 and a high of 28.6 per 100,000 in 1992. Between the Years 1994 and 2003, there has been an estimated annual decrease of 4.5% in mortality rates for prostate cancer. Between 1988 and 2003, the annual death rates for black males were 1.8 to 2.1 times higher than the rates for white males. For the period 1998-2003, Michigan residents lost a total of 59,490 years of life due to prostate cancer. The average number of years of life lost for men dying of the disease in 2003 was 9.5. (Years-of-life-lost calculations for people who die are based upon gender and race-specific life expectancy tables.) In 2002, there were 4,491 hospital discharges in Michigan of patients whose primary diagnosis was prostate cancer. The average length of stay was 2.98 days.

In 2002, for its regular Michigan subscribers, Blue Cross and Blue Shield paid \$34,429,664 on claims for all phases of treatment of prostate cancer, an average of \$7,651 per case. During the same period, Medicare Part A paid an average of \$4,376 per case. It is worth noting that these figures do not include out-of-pocket payments for deductibles, co-payments, medications, transportation, and other non-covered items. Likewise, they also do not reflect lost wages and opportunity costs of patients and their family members or other care givers. Thus, these numbers represent the minimum documented costs of cancer care in Michigan. They are useful as an indication of the magnitude of expenditures and in comparing the costs of the specific cancers. If tracked over time, the data would demonstrate one facet of progress in cancer control.

The above cost data does not capture the expenditures for men who are uninsured or underinsured or the lack of appropriate treatment of these men. A fundamental effort for any cancer control plan should be supporting efforts to make diagnostic and treatment modalities available to all men regardless of insurance status.

In addition to incidence, mortality, and cost, morbidity associated with prostate cancer and with the treatment of prostate cancer is a critical measure of the burden of this disease, especially in light of the relatively long survival time of most men with prostate cancer compared to other

cancers. There is a need to develop or adapt tools to track morbidity in prostate cancer populations as measured by changes in the quality of life of survivors including physical, psychosocial, and functional indicators.

*(Data in this introduction is from **The Cancer Burden in Michigan: Selected Statistics**, prepared by the Michigan Public Health Institute in support of the Michigan Cancer Consortium Initiative, December 2005. For more complete information, see Appendices E and F.) Also available at www.michigancancer.org/Resources/SpecialMCCReports.cfm*

Prostate Cancer Control Recommendations for Primary and Secondary Prevention

Goals, Progress Markers, Rationale, Objectives, Strategy Options

Primary and Secondary Prevention Goal

Increase, by 2010, awareness of prostate cancer risk factors as well as the benefits and risks of prostate cancer screening among primary care physicians, high-risk men, and the general public.

Progress Markers

The Michigan Cancer Consortium (MCC) will know if progress is made toward increasing awareness of prostate cancer risk factors and the benefits and risks of screening among primary care physicians, high risk men, and the general public by:

- Repeating the 1995 randomized Prostate Cancer Knowledge, Attitudes and Practices survey of physicians
- Conducting chart reviews among Michigan Health Plans to assess documentation of counseling about prostate cancer
- Repeating the 2001-02 Special Cancer Behavioral Risk Factor Survey to determine changes in reported counseling from primary care providers about prostate cancer testing risks and benefits, and reported receipt of a PSA test among men in both high risk and average risk populations
- Conducting audits of health plan data, in conjunction with HEDIS analysis, to obtain baseline information about utilization of PSA testing by primary care physicians.

Why This Priority Is Important

The high incidence of prostate cancer, and its excessive burden among African American men, makes it an important target for cancer control. Baseline data gathered in 1995 along with the advice of consumer and professional groups led the MCC to develop *Recommendations for Prostate Cancer Screening, 1997*. Subsequently two objectives were proposed to increase knowledge among primary care physicians, and among the public and high-risk populations. This objective was not the chosen Consortium priority in 1998, but even so, several initiatives were undertaken to increase knowledge among primary care physicians, the public, and high-risk men. It was expected that the increase in knowledge would result in careful, informed decision-making about whether or not to participate in screening. It was also presumed that physicians would be aware of the excessive burden on African American men and more likely to counsel them about their risk and the issues about screening and its sequelae.

Summary of Science and Issues Related to Prevention

Risk assessment: Individualized risk assessment based on risk factors and risk reduction factors should inform the decision whether or not to get screened for prostate cancer.

Major risk factors are increasing age, African ancestry, and positive family history.⁴ For more complete information see Appendix A. Chemoprevention with finasteride has been shown to decrease the overall risk of prostate cancer, but it increases the risk of aggressive disease slightly.⁵ Epidemiological studies have suggested antioxidants (such as lycopene and Vitamin E) may be effective in reducing the risk of prostate cancer; clinical trials are underway.

Knowledge among primary care providers: Professional and scientific groups still differ on PSA screening recommendations. The American Urological Association and the American Cancer Society advocate offering screening annually beginning at age 50. The National Cancer Institute and the U.S. Preventive Services Task Force do not recommend PSA screening. The American College of Physicians and the American Academy of Family Physicians, both representing primary care providers, advocate a shared decision-making model, in which the patient/significant other decide along with the health care provider whether or not to be screened. Most groups that recommend screening suggest that screening begin at age 50 with both PSA and DRE, with age of screening onset lowered to age 40-45 for high-risk populations, particularly African Americans. The MCC Advisory Committee on Prostate Cancer recommends considering screening in high-risk populations at age 45. A key difference among those supporting screening is that some groups unequivocally advise screening, while others are more cautious; indicating that conclusive data demonstrating efficacy (e.g., a decrease in mortality rate attributable to screening) is still pending.

Testing for Prostate Cancer:

Evidence is weak for the use of DRE in screening for prostate cancer; therefore, the following issues pertain to the use of PSA as a screening test.

- PSA is a good screening test.⁶ Sensitivity and specificity are high, and positive predictive values are 30% for Caucasians and 45% for African Americans.
- Reliability of PSA suggests a need for caution. For PSAs greater than 4, between 15% and 30% will test normal (under 4) on repeat sampling.
- Significant percentages of men with PSAs below the normal cutoff of 4 have prostate cancer. For example, 5% of men with PSAs under 2 have prostate cancer.⁷
- PSA velocity may predict the aggressiveness of the disease. A recent study⁸ showed that men with a rapidly rising PSAs prior to prostatectomy were found to have more aggressive disease relative to those men showing a gradual rise of pre-surgical PSA levels.

⁴ Klein, E. (2005). Can Prostate Cancer Be Prevented? *Nat Clin Pract Urol*, 5. Retrieved from www.medscape.com/viewarticle/498004.

⁵ Thompson, I.M., Goodman, P.J., Tangen, C.M., et al. (2003). The influence of finasteride on the development of prostate cancer. *NEJM*, 349(3), 215-224.

⁶ Barry, M. (2001). Prostate-Specific-Antigen testing for early diagnosis of prostate cancer. *NEJM* 344 (18). Retrieved December 22, 2004 from www.nejm.org.

⁷ U.S. Preventive Services Task Force. (2002). Screening for prostate cancer: recommendation and rationale. *Annals of Internal Medicine*, 137(11). Retrieved from www.annals.org.

⁸ D'Amico, A.V., Chen, M-H., Roehl, K.A., & Catalona, W.J. (2004) Preoperative PSA velocity and the risk of death from prostate cancer after radical prostatectomy. *N Engl J Med*, (351), 125-135.

- A number of biomarkers that would distinguish indolent from aggressive prostate cancer are being investigated.⁹
- Lead time bias due to PSA screening is estimated to be from 4 to more than 15 years. This range makes it difficult to develop predictive models on the efficacy of screening.
- Use of descriptive, epidemiologic data to prove or disprove screening efficacy using PSA is difficult. This is underscored by a study of two geographic areas showing that although the areas had widely different rates of PSA screening, both showed equal trends of decreased mortality after the onset of PSA screening.¹⁰
- The gold standard for screening efficacy is whether or not mortality rates are positively impacted. These data cannot be derived without prospective randomized trials. The results of these trials, such as the PLCO trial in the U.S., are not due for another six to ten years. Some investigators fear that contamination of the control group may invalidate the results of the PLCO trial and possibly other trials.

The 2005 MCC Advisory Committee on Prostate Cancer (ACPC) concluded that screening issues need to be addressed and that there should be clear guidance for physicians and men in Michigan. The group felt the committee must advocate for patients using the preponderance of evidence and their collective judgment about who should be screened for prostate cancer. Biologic differences exist and need to be addressed. Informed and shared decision making with patients contemplating prostate cancer screening is crucial, but the ACPC acknowledged that time and knowledge continue to be barriers to shared decision making about screening and treatment decisions for primary care providers. They recommended that primary care physicians should continue to be targeted with education and tools related to prostate cancer screening. To that end, the 1997 Prostate Cancer Screening Recommendations were revised. See Appendix A for the MCC Prostate Cancer Early Detection Recommendations, 2005.

It is still unclear if primary care physicians understand prostate cancer risk factors or regularly counsel men about screening. Results of the 2001-2002 Special Cancer Behavioral Risk Factor Survey indicate that over half of Michigan men ages 50 and older in all population groups who had prostate cancer screening tests reported that their doctor discussed the advantages and disadvantages of PSA testing. African Americans (58.4%) were least likely to report that discussion had taken place and Arab Americans most likely (85.8%)¹¹. Men aged 50-64 were more likely to have had that discussion than were men 65 and older. However, while in general, more than half of men surveyed reported having had a PSA test, there were differences by population group and by age. Only slightly more than 40% of African American men ages 50-64 said they had been screened with PSA. The Advisory Committee recommends measuring the degree to which physicians understand prostate cancer risk factors and screening, how frequently they document discussion about screening among male patients, and the degree to which screening is provided by primary care physicians.

⁹ Eisenberger, M., Partin, A. (2004). Progress toward identifying aggressive prostate cancer. *NEJM*, 351(2). Retrieved July 8, 2004, from www.nejm.org.

¹⁰ Lu-Yao, G., et al. (2002) Natural experiment examining impact of aggressive screening and treatment on prostate cancer mortality in two fixed cohorts from Seattle area and Connecticut. *BMJ*, (325). Retrieved January 20, 2005 from www.bmj.com.

¹¹ Michigan Department of Community Health and Michigan Public Health Institute. *The 2001-2002 Special Cancer Behavioral Risk Factor Survey*. Retrieved from www.michigancancer.org/PDFs/MCCReports/MCCReports-SCBFRS-043004.pdf.

The Michigan Association of Health Plans represents 25 health plans throughout the state. Every health plan has guidelines that it uses to ensure members receive appropriate evidence-based care, and each may be different. Health plans usually send a one-page list of guidelines to the providers in their networks, and most providers are affiliated with more than one health plan. Guidelines sent out by the state to providers may not be the same as those recommended by a particular health plan and may be ignored. Not all Health Plans have a guideline for prostate cancer screening. Distribution of the 2005 MCC recommendations might increase the use of risk assessments among primary care physicians in the absence of uniform early detection recommendations and help them assist men to weigh the pros and cons of testing with PSA and DRE on an individual basis.

Knowledge among the public and high-risk populations

A 1998 objective was to increase knowledge 20% among these populations by 2002. The 1995 survey would be used as the baseline. Several initiatives have been undertaken but there are still disparities by age and population group in early detection rates and in mortality. It is not known if the initiatives have worked or to what extent the public's and high-risk populations' knowledge have increased about prostate cancer signs and symptoms, risk factors, early detection recommendations and procedures, and the impact of a positive diagnosis. African American men are less aware of risk factors for prostate cancer than other men who are at lower risk.¹² If knowledge gaps still exist, the Advisory Committee believes more could be done to make the public and high-risk populations aware of risk factors for prostate cancer, the issues related to early detection procedures, and the impact of a positive diagnosis.

Prostate Cancer Screening: A Decision Guide and *Prostate Cancer Screening: A Decision Guide for African Americans* from the CDC and *Making the Choice: Deciding What to Do About Early Stage Prostate Cancer* from the Michigan Cancer Consortium are excellent products. A booklet on survivorship issues may need to be developed.

These booklets need to be widely distributed to help men make rational decisions around prostate cancer issues. Existing networks and opportunities such as AARP, unions, women's groups, existing screening sites, and driver's license renewal processes could be used to reach men and their families/friends. Most companies that offer cafeteria health care plans could distribute the booklets during the sign up process. Short, pointed informational messages such as:

- Do you know that prostate cancer strikes 1 man in 6?
- Do you know your PSA?

could be designed to make the public aware enough to ask their primary care physician a question in order to start the discussion. The information would be adaptable to short messages (posters in the workplace) just to plant a thought, and attempt to get a man to visit his healthcare provider to discuss prostate cancer screening.

¹² Woods, V.D., Montgomery, S.B., Belliard, J.C., et al. (2004) Culture, black men, and prostate cancer: what is reality? *Cancer Control*, 11(6z), 388-396.

PSA Utilization

The MCC Prostate Cancer Early Detection Recommendations indicate a combination of DRE and PSA should be used to test for the presence of prostate cancer. Measurement of DRE utilization would require chart review for documentation on a physical examination. Since the PSA requires laboratory analysis using a specific procedure code, analysis of PSA utilization could be more efficient. The PSA might serve as a surrogate measure of prostate cancer testing. Assessment of current PSA utilization in Michigan would provide baseline data for use if and when population screening, or screening of high-risk populations, is widely supported. Analysis of administrative data sets from health plans could provide some indication of current use. While utilization data may not include race, data could be analyzed by zip code and by age cohorts (ten year increments).

Health plans know the ethnic and racial composition of persons residing in the various Michigan zip codes. To do this analysis, the methodology (numerator and denominator) would have to be identified after which the health plan could be asked if they would be willing to do this assessment. Results could provide information about utilization of PSA testing and which age, race, socioeconomic status and co-morbid disease status are associated with lower utilization of PSA testing. In addition to analysis of administrative data, chart reviews are conducted by health plans to determine adherence to HEDIS measures that are not included in the data set from clinical procedures (B/P for example). It has been suggested that during this process of chart review, chart reviewers could also look for evidence that prostate cancer screening/counseling was discussed. Reviewers could also look to see if there was documentation of family history of prostate cancer. The MCC could take appropriate actions in the future to address identified deficiencies.

What Needs to Be Done

Even though it is still unclear that prostate cancer screening benefits the general population of men of average risk, all men and their providers should be aware of the issues. High-risk populations should be well informed of their increased risk and the potential benefits and risks of early detection. It is important that providers understand prostate cancer risk factors, and that they identify and counsel men at high risk about early detection procedures. Managed care plans offer an opportunity to monitor the extent to which risk assessments guide counseling about prostate cancer testing and provide baseline information about PSA utilization.

Objective

Increase by 2010 awareness of prostate cancer risk factors as well as the benefits and risks of prostate cancer screening 30% among primary care physicians (Baseline: 2006 KAP survey of physicians), and 30% among high risk men and the general public (Baseline: 2006 SCBRFS).

Objective

By 2010, increase from 70% to 80%, the awareness of prostate cancer risk factors among African American men. (Baseline to be measured by the 2006 SCBRFSS)

Strategy Options

- Disseminate the 2005 revised early detection recommendations among health providers, particularly primary care physicians, through existing networks such as to MAHP, MQIC, and at medical meetings.
- Encourage the MAHP and MQIC to adopt a recommendation for doing risk assessments while counseling men about the efficacy of prostate cancer testing.
- Widely disseminate existing prostate cancer screening booklets (CDC), the decision tree (MDCH), booklets on treatment options, and information on ongoing care/survivorship issues to the public.
- Produce a series of informational articles as part of a public campaign, similar to public education breast cancer and heart disease campaigns, to increase awareness of prostate cancer incidence, risk factors, and issues.
- Develop educational efforts that target African American men.

Objective

By 2010, there will be a 30% increase in adherence to the 2005 Michigan Cancer Consortium prostate cancer early detection recommendations among primary care physicians, with particular emphasis on populations of higher than average prostate cancer risk.

Strategy Options

- Determine and monitor utilization of PSA testing among high-risk men by analysis of health plan data.
- Repeat SCBRFS to assess change in reported receipt of counseling and testing.

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Prostate Cancer Control

Recommendations for Treatment

Goal, Progress Markers, Rationale, Objectives, Strategy Options

Prostate Cancer Treatment Goal

By 2012, a higher proportion of men with localized/regional stage prostate cancer on Watchful Waiting and men with advanced or recurrent prostate cancer will receive appropriate surveillance and/or active treatment including increased enrollment in clinical trials.

Progress Markers

- Tools developed that will be used to establish a baseline and to monitor the percentage of men with localized/regional stage prostate cancer on Watchful Waiting that are not receiving appropriate cancer specific follow up.
- Tools developed that will be used to establish a baseline and to monitor the percentage of men with advanced or recurrent prostate cancer who receive appropriate active treatment and/or are enrolled in clinical trials.
- Complete surveys and/or analysis of information from cancer registries to evaluate the percentage of men with localized/regional stage prostate cancer on Watchful Waiting that are not receiving appropriate cancer specific follow up.
- Complete surveys and/or analysis of information from cancer registries to evaluate the percentage of men with advanced or recurrent prostate cancer who receive appropriate active treatment and/or are enrolled in clinical trials.

Why This Priority Is Important

Prostate cancer is different from other cancers in that the majority of individuals diagnosed with the disease at an early stage would not die of the disease if left untreated. However, the minority with aggressive disease face as dismal a prognosis as that of other cancers; prostate cancer remains the number two cause of cancer related mortality in Michigan men.¹³

Sometimes the indolent or aggressive nature of the prostate cancer is evident at the time of diagnosis. However, for those men for whom it is not clear, there is a difficult quandary. Should they pursue an active treatment course that will probably be curative but may leave them with significant long term quality of life problems in the domains of urinary symptoms, bowel symptoms, sexual dysfunction, and hormonal related symptoms—when the disease may not have affected lifespan or caused significant problems?

¹³ Michigan Public Health Institute. *The Cancer Burden in Michigan: Selected Statistics 1985-2002*. December 2004.

The efforts of the MCC Prostate Cancer Action Committee over the past six years was to develop, evaluate and distribute a patient decision aid to facilitate an informed decision making process in the face of this quandary for men diagnosed with localized prostate cancer.¹⁴

At this time, additional treatment issues need to be addressed. Some individuals with an early, indolent type of prostate cancer will choose to defer active treatment while having regular follow up visits and testing to watch for indications that the cancer may be becoming more aggressive or spreading; this is called Watchful Waiting or Active Surveillance. Men who choose Watchful Waiting may have a higher anxiety level than those who choose active treatment.¹⁵ These individuals endure the stress of living with an untreated cancer even though intellectually they understand that the prostate cancer is unlikely to be the cause of death.^{16, 17} It is likely that this anxiety could be at least partially alleviated if the answers to questions such as these were more accessible to patients, their families, and their primary care physicians:

- Do I really have cancer if it doesn't need to be treated?
- Can I change my mind and get active treatment?
- What, if any, follow-up is necessary for optimal care?
- What symptoms would mean that the cancer is progressing?

Impending changes in the definition of cancer versus precancerous conditions based on pathology reports of biopsy specimens may further confound the issues. Preliminary results of the 2005 Pathology Consensus Panel include a recommendation that Gleason scores 2-4 and some Gleason score 5 specimens should not be labeled prostate cancer but one of two precancerous conditions.

Some men may be inappropriately placed on Watchful Waiting. African American men have been shown to be less likely than white men to receive active therapy even though, on average, they present with higher tumor grade and stage at the time of diagnosis.¹⁸ While some of these men may make a fully informed decision, some may be directed away from active treatment modalities.

Different dilemmas confront individuals with advanced disease at the time of diagnosis or with recurrent disease. These men are often given the message explicitly or implicitly that nothing can be done despite the fact that recent advances have shown that androgen independent disease can sometimes be treated with chemotherapy or Androgen Deprivation Therapy with

¹⁴ Michigan Cancer Consortium. *Making the Choice: Deciding What to Do About Early Stage Prostate Cancer*. 2003.

¹⁵ Braslis, K.G., Santa-Cruz, C., & Brickman, A.L., et al. (1995) Quality of life 12 months after radical prostatectomy. *Br J Urol*, (75), 48-53.

¹⁶ Cowen, M.E., Cahill, D., & Dattan, M.W., et al. (1996) The value or utility of prostate cancer states. *J Urol*, (155), 376.

¹⁷ Herr, H.W. (1997) Quality of life in prostate cancer patients. *CA—A Cancer Journal for Clinicians* (47), 207-217.

¹⁸ Underwood, W., et al. (2004) Racial/ethnic disparities in the Rx of localized/regional prostate cancer. *J Urol*, (171), 1504-1507.

chemotherapy for a survival advantage.¹⁹ Chemotherapy and Radiation modalities are also underutilized for symptom palliation. Clinical trials have been slow to fill, making it more difficult to find better treatments for advanced prostate cancer.

What Needs To Be Done

Michigan men, their families and their primary care providers need clear, up-to-date, complete, culturally sensitive, easily accessible information on when Watchful Waiting is an appropriate treatment option. When Watchful Waiting is selected, information is then needed on current prostate cancer specific follow-up testing and the indications that the disease has progressed to the point at which active treatment should again be considered.

Men with advanced or recurrent prostate cancer and their primary care providers likewise need access to the most up to date information on survival-prolonging and palliative treatment modalities.

Therefore, the following objectives are proposed:

Objective

By 2012, the proportion of men with localized/regional stage prostate cancer on Watchful Waiting who are not receiving cancer specific follow-up will be measured through the use of surveys and/or cancer registries.

Based on these findings, develop means to improve the proportion of men with localized/regional stage prostate cancer on Watchful Waiting who receive appropriate prostate cancer specific follow up care.

Strategy Options

- Conduct studies to determine the most appropriate interval for periodic examination of patients managed by the Watchful Waiting approach.
- Conduct studies to determine the appropriate endpoint that defines when the Watchful Waiting approach should be replaced with active treatment.
- Develop and disseminate information to patients, their families, and providers about appropriate follow up with Watchful Waiting.

Objective

By 2012, the percentage of men diagnosed with advanced or recurrent prostate cancer that receive active treatment and/or are enrolled in clinical trials will be measured through the use of surveys and/or cancer registries.

¹⁹ Petrylak, D.P., Tangen, C.M., Hussain, M., Jones, J., Taplin, M.E., Burch, P.A., Berry, D.L., & Crawford, E.D. (2004) Docetaxel and estramustine versus mitoxantrone and prednisone: results of SWOG intergroup protocol 9916. *N Engl J Med*, 35(15), 1513-20.

Based on these findings, develop means to improve the percentage of men diagnosed with advanced or recurrent prostate cancer who receive active treatment and/or are enrolled in clinical trials.

Strategy Options

- To support existing and/or develop information resources such as hotlines and directories for men diagnosed with advanced or recurrent prostate cancer.
- Develop and disseminate information to patients with advanced or recurrent prostate cancer, their families, and providers about the appropriateness of active treatment and/or clinical trials.

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Prostate Cancer Control Recommendations for Survivorship

Goal, Progress Markers, Rationale, Objectives, Strategy Options

Prostate Cancer Survivorship Goal

By 2010, practice guidelines and educational materials will be available for professionals and survivors/families that address prostate cancer symptom management across the survivor continuum to decrease morbidity.

Progress Markers

How will the MCC know if progress is made toward achieving this prostate cancer priority? The following markers will be utilized:

- Tools to track morbidity indicators in populations have been developed or adapted.
- Practice guidelines for prostate cancer symptom management have been developed for providers.
- Educational materials for prostate cancer symptom management have been developed for survivors and families.

Why This Priority Is Important

National Cancer Institute (NCI) publications define a person as a cancer survivor from the time the individual is diagnosed with cancer through the balance of his or her life. The director of the NCI stated, “We are beginning to view cancer not only as an acute disease to be eradicated, but as a disease that people live with and don’t die from.”²⁰ Additionally, NCI has defined cancer prevalence as “...the numbers of people alive today who have been diagnosed with cancer which includes individuals who are newly diagnosed, in active treatment, have completed active treatment, and those living with progressive symptoms of their disease”.²¹ Historically, people diagnosed with cancer that lived 5 years or more, post-diagnosis, were considered ‘cured’ of cancer. In 2004, the NCI in partnership with Centers for Disease Control (CDC) reported that the prevalence of cancer survivors living in the United States had increased from 3.0 million (1.5% of the U.S. population) in 1971 to 9.8 million in 2001 (3.5% of the U.S. population).²² A national health objective for 2010 was identified to increase, to 70%, the proportion of cancer patients who are living 5 years or longer after diagnosis.²³

²⁰ Hightower, D., & Vaughn, P. (2003) Survivorship and the changing role of palliative care. *Benchmarks* (e-journal). U.S. National Institutes of Health, National Cancer Institute, 3(4), Retrieved from www.nci.nih.gov/newscenter/benchmarks-vol3-issue4.

²¹ U.S. National Institutes of Health, National Cancer Institute (NCI). Estimated U.S. cancer prevalence counts: definitions. Retrieved July 19, 2005 from <http://dcccps.nci.nih.gov/ocs/prevalence/definitions.html>.

²² Centers for Disease Control and Prevention (CDC). (2004) Cancer survivorship—United States, 1971-2001. *MMWR Morbidity Mortality Weekly Report*, 53(24), 526-529.

²³ Centers for Disease Control and Prevention (CDC) and Lance Armstrong Foundation. (2004) A national action plan for cancer survivorship: advancing public health strategies. Retrieved from www.cdc.gov/cancer/survivorship/survivorpdf/plan.pdf.

The CDC reported in 2004 that men who had a primary diagnosis of prostate cancer were the second largest group of cancer survivors, representing 17% of all cancer survivors in the United States. At the beginning of 2003, there were an estimated 81,417 prostate cancer survivors living in Michigan, and an additional 8,540 Michigan men were diagnosed with new cases of prostate cancer in 2004. The American Cancer Society reported that prostate cancer incidence rates between 1988 and 1992 "...increased dramatically due to earlier diagnosis..." African American men, in the U.S. and in Michigan, experienced both the highest incidence and mortality rates for prostate cancer.^{24,25}

Although the number of prostate cancer survivors is increasing and considerable progress has been made in the treatment of prostate cancer, little information is available to assist men and their families with survivorship issues. One of the most troubling aspects of survivorship, identified by prostate cancer survivors and their families, is managing symptoms that have resulted from the disease or the treatment for it. Available research indicates men experience erectile dysfunction, urinary incontinence, rectal incontinence, and hormonal imbalance *in varying degrees* as a result of prostate cancer and/or treatment. These symptoms can extend for a number of years following treatment and are associated with lower quality of life and more emotional distress among men and their partners. However, men with prostate cancer typically are followed for only six months by their cancer specialist and then referred to primary care providers. Primary care providers are often unaware of cancer survivor issues or lack time in their brief provider-patient encounter to address survivor issues.

What Needs To Be Done

The experience of prostate cancer can have long-term effects on the health related quality of life (HRQOL) of the men and their families that include physical, functional, psychological, and social changes. At this time there are no prostate-specific practice guidelines in Michigan to assist health care professionals to provide ongoing care to survivors and their family members. Health care professionals who interact with survivors and their families across the continuum of care at the time of diagnosis, before and after treatment, as well as during active surveillance with 'watchful waiting' are in key positions to assess and address HRQOL concerns for prostate cancer survivors and their partners. HRQOL endpoints are being included in clinical trials for prostate cancer treatment to measure changes in physical, functional, psychological, and social health.²⁶

In addition to practice guidelines, there is also a need for professionals, survivors and families to have access to the latest educational materials on prostate cancer symptom management. To date, information is lacking on the number of prostate cancer survivors/families who have received culturally appropriate educational materials on prostate cancer symptom management or been informed about community resources to address their needs. Since provider-patient encounters are typically very brief, there is little time for teaching especially in areas related to

²⁴ Centers for Disease Control and Prevention (CDC). 2004 Cancer Burden Data Fact Sheets Michigan.

²⁵ Michigan Public Health Institute. The Cancer Burden in Michigan: Selected Statistics 1985-2002. December 2004.

²⁶ Wei, J.T., Dunn, R.L., Sandler, H.M., McLaughlin, P.W., Montie, J.E., Litwin M.S., Nyquist, L., & Sanda, M.G. (2002) Comprehensive comparison of health-related quality of life after contemporary therapies for localized prostate cancer. *Journal Clinical Oncology*, 20(2), 557-566.

prostate cancer survivorship issues (e.g., incontinence, erectile dysfunction, hormone imbalance). In order for survivors to participate fully in maintaining their own well being and quality of life following the diagnosis and treatment of prostate cancer, they need access to well-developed, evidence-based educational materials. These materials need to be culturally appropriate and at a reading level Michigan residents can comprehend. Because family members, especially partners, are the primary source of physical and emotional support to prostate cancer survivors, educational materials also need to be family-centered and address issues relevant to family caregivers.

Objective

By 2010, develop and distribute *practice guidelines* for prostate cancer symptom management to Michigan primary care providers and pertinent specialists.

Prostate cancer symptom management practice guidelines will help clarify the standard of care in the State of Michigan. It is important that all health care providers know the practice guidelines and can implement them. It is also important that patients and their families be informed about the practice guidelines so that they can know the expected standard of care.

Strategies

- Identify the content essential to symptom management for the different phases of prostate cancer survivors.
- Develop provider practice guidelines for prostate cancer symptom management that are age-specific and culturally appropriate.
- Develop strategies to facilitate ongoing implementation of the prostate cancer symptom management guidelines during the critical transition from specialty care to follow-up care by primary care providers.
- Develop a process to distribute the practice guidelines to health care providers as well as to survivors and families in Michigan.
- Develop a method to evaluate the effect of the practice guidelines on the health related quality of life of survivors and families in Michigan.

Objective

By 2010, develop and distribute *educational materials* for prostate cancer symptom management to prostate cancer survivors and their families that are culturally sensitive, age-specific, and at an appropriate reading level.

Strategies

- Identify the needs of prostate cancer survivors through a review of the literature and the use of focus groups.
- Identify existing educational materials relevant to prostate cancer survivors/families that will address their information needs.
- Identify gaps in existing prostate cancer educational materials.
- Adopt, adapt, or develop patient educational material for prostate cancer survivors and their family members.

- Develop a process to distribute prostate cancer symptom management educational materials to providers and survivors/families in Michigan.
- Develop a method to evaluate how the utilization of educational materials affects the health related quality of life of survivors and families in Michigan.

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Appendix A:

Michigan Cancer Consortium Prostate Cancer Early Detection Recommendations (Updated 2005)

These recommendations have been developed by the Michigan Cancer Consortium Advisory Committee on Prostate Cancer to help Health Care Providers guide asymptomatic men and their families in making informed decisions about prostate cancer early detection.

Men who MAY be candidates for early detection*:

- Prostate cancer is a disease of older men. Early detection beginning at age 50 may be appropriate for men who have a life expectancy of at least 10 years. Seventy percent of prostate cancer incidence is in men older than 65 though prostate cancer in men less than 50 is more likely to be aggressive.
- Higher risk men may be candidates for early detection starting at age 45. Men at higher risk are:
 - African Americans have an incidence rate of prostate cancer 1.4 times that of Whites, and a disease specific mortality rate 1.9 times that of Whites.²⁷
 - Men with a family history of prostate cancer on either maternal or paternal side: There is a two fold increase in lifetime risk in individuals with one affected first degree relative. This increases to a 4.5 fold increase with 2 affected first degree relatives, and an eleven fold increase with 3 affected first degree relatives. This increased risk for prostate cancer attributable to family history is consistent across all racial and ethnic backgrounds.²⁸
 - Men with a strong family history (for example young age at diagnosis or multiple family members) should also receive risk information and counseling.
 - BRCA1 mutation carriers have a two times higher risk of prostate cancer than non-carriers; BRCA2 mutation carriers have 5-7 times the risk, especially for early onset prostate cancer.²⁹

Men who are NOT candidates for early detection:

- Men who are younger than 50 who are at normal or low risk.
- Men of any age with less than 10 year life expectancy.
- Men with suspected or known prostate cancer or history of prostate cancer.

Men with symptoms of prostatic disease should undergo diagnostic evaluation.

****All candidates for early detection should be fully informed of the potential risks and benefits of early detection before being tested.***

²⁷ Michigan Public Health Institute. *The Cancer Burden in Michigan: Selected Statistics, 1985-2002*. December 2004.

²⁸ Bock, C. The Genetics of Prostate Cancer. Karmanos Cancer Institute, Wayne State University. Presentation to MDCH Cancer Section, June 10, 2005.

Informed Decision-Making: Counseling by a health professional should include the following elements:

- Prostate cancer is an important and potentially life-threatening health problem.
- The benefits of one-time or repeated testing for prostate cancer have not yet been proven, but early detection may save lives.
- Early detection and treatment may prevent future prostate cancer-related illness.
- Treatment of prostate cancer does have risks that should be carefully evaluated prior to the decision for treatment. Treatment may result in sexual dysfunction, urinary incontinence, fecal incontinence, rectal bleeding, and a minimal risk of treatment-induced mortality.
- Both digital rectal examination and PSA measurement can have false positive or false-negative results.
- An abnormal test result may require further evaluation, usually ultrasound directed biopsies of the prostate.
- The risk of developing prostate cancer increases with increasing age.
- African-American men have a higher risk of getting and dying from prostate cancer than men in other racial/ethnic groups.
- Men with a family history of prostate cancer on either the maternal or paternal side are at higher risk of getting and dying from prostate cancer. These men should receive genetic counseling.
- Men and their families may be provided access to the CDC decision aids “Prostate Cancer Screening A Decision Guide” and/or “Prostate Cancer Screening A Decision Guide for African Americans” (available free of charge at www.cdc.gov/cancer/publica.htm#printed) or to another high quality decision aid to assist in making an informed decision.

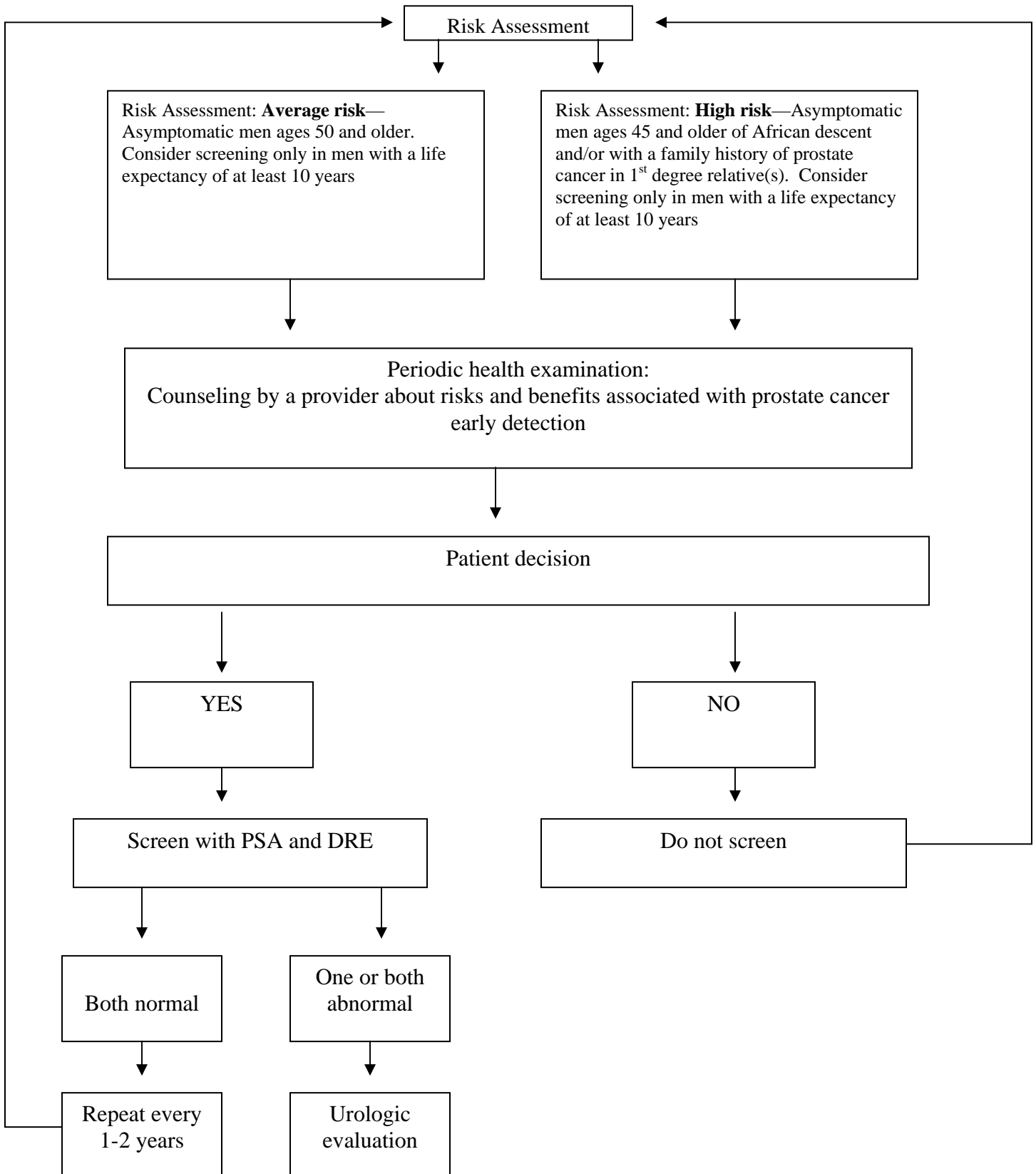
Health Care Providers should then:

- Address any patient concerns.
- Facilitate a shared decision making process on early detection for prostate cancer.
- **IF** the man chooses to be tested, **both** a PSA and a DRE should be done.

When an early detection test or biopsy results are indicative of prostate cancer, refer men and family members to:

- The Michigan Cancer Consortium decision aid “Making the Choice: Deciding What to Do About Early Stage Prostate Cancer,” which is available free of charge at www.prostatecancerdecision.org or by calling 800-249-0314.

Michigan Cancer Consortium Prostate Cancer Early Detection Recommendations (Updated 2005)



Appendix B:

Hereditary Prostate Cancer

Of the 1 in 6 American men who will develop prostate cancer in their lifetime, approximately 5-10% are in Hereditary Prostate Cancer (HPC) families. An additional 20% of men with prostate cancer have a single affected family member.

Older age, being of African descent, and a positive family history of prostate cancer have long been recognized as risk factors, but understanding the complex genetic and environmental influences and mechanisms underlying this disease are at an early stage.²⁹ As a result of genetic studies to date, it may be said that genetic heterogeneity is very likely in prostate cancer as are gene-gene and gene-environment interactions.³⁰

Genetic Mechanisms in the development of prostate cancer

Gene mutations that play a part in the initiation or progression of prostate cancer include the following mechanisms:

- Decreased RNA degradation activity
- Increase in testosterone biosynthesis
- Increase in the conversion of testosterone to dihydrotestosterone, the more metabolically active form, which stimulates cell division in androgen dependent prostate cancers.
- Associated with inflammation
- Abnormal proliferation or a decrease in apoptosis or programmed cell death
- Decreased carcinogen detoxification³¹

Hereditary Prostate Cancer

The Hopkins clinical criteria for HPC require at least one of the following:

- Three or more affected first-degree relatives
- A prostate cancer case in three generations on either the maternal or paternal side of the family
- Any two family members diagnosed before age 55³²

Hereditary prostate cancer is generally inherited in an autosomal mode including BRCA1 and BRCA2 gene mutations which represent a very small fraction of hereditary prostate cancers. There is some epidemiologic evidence for X-linked and/or recessive inheritance patterns in some hereditary prostate cancer families as well; in these families men have an increased risk when a brother is affected as compared to a father.

²⁹ Schaid, D. (2004) The complex genetic epidemiology of prostate cancer. *Human Molecular Genetics*, 13(Review Issue 1), R103-R121.

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³² Smith, J.R., Freije, D., Carpten, J.D., et al. (1996) Major susceptibility locus for prostate cancer on chromosome 1 suggested by a genome-wide search. *Science*, 274, 1371.

Public Health Implications

Patient educational materials including decision aids need to be accessible to fully inform men of their personal risk status, of available screening options, and of the benefits and risks of testing and treatment options. Genetic counseling should be available regardless of insurance or financial status for men with a strong family history of prostate cancer or a family with a known BRCA1 or BRCA2 mutation.

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12. Wu, Y.Q., Chen, H., Rubin, M.A., Wojno, K.J., & Cooney, K.A. (2001) Loss of heterozygosity of the putative prostate cancer susceptibility gene HPC2/ELAC2 is uncommon in sporadic and familial prostate cancer. *Cancer Res*, 61(24), 8651-8653.

Appendix C:

Prostate Cancer Resources

Websites

American Cancer Society: www.cancer.org (800-ACS-2345)

American Foundation for Urologic Diseases: www.afud.org (800-828-7866)

CancerCare: www.cancercare.org (800-813-4673)

CDC: www.cdc.gov/cancer/prostate

Institute of Medicine report on survivorship (11/7/05): www.iom.edu/report.asp?id=30869

Intercultural Cancer Council: <http://iccnetwork.org> (713-798-4617)

Lance Armstrong Foundation: www.laf.org (512-236-8820)

Memorial Sloan-Kettering Cancer Center (Hereditary prostate cancer):
www.mskcc.org/mskcc/html/8625.cfm

National Cancer Institute Cancer Information Service: www.nci.nih.gov (800-4-CANCER)

National Comprehensive Cancer Network (Treatment Guidelines for Patients): www.nccn.org
(999-909-6226)

The Prostate Net: www.prostate-online.com (888-4ProsNet)

Us Too International Prostate Cancer Education & Support Network: www.ustoo.org
(800-808-7866)

The Wellness Community: www.thewellnesscommunity.org

Books and Reports

Center for Disease Control and Prevention and Lance Armstrong Foundation. (2004) *A national action plan for cancer survivorship: advancing public health strategies*. Atlanta: CDCP.

Intercultural Cancer Council Baylor College of Medicine. (2004) *Cultural competence in cancer care: a health care professional's passport*. Houston: Baylor College of Medicine.

National Guideline Clearinghouse Guideline synthesis: Screening for prostate cancer 1998 Dec 28 (updated 2005 September). www.guideline.gov

Schwartz, A.L. (2004) *Cancer fitness: exercise programs for patients and survivors*. New York: Simon and Schuster.

Williams, C.R. & Williams, V.A. (2003) *That black men might live: my fight against prostate cancer*. Roscoe: Hilton Publishing Company.

Decision Aids

Center for Disease Control and Prevention

- *Prostate Cancer Screening A Decision Guide*
- *Prostate Cancer Screening A Decision Guide for African Americans*

Order limited quantities free of charge: www.cdc.gov/cancer/publica.htm#printed

Michigan Cancer Consortium

- *Making the Choice: Deciding What to Do About Early Stage Prostate Cancer*

Free of charge to Michigan individuals and organizations. Limited quantities available at no cost out of state; order at cost above limit from out of state and all out of country orders:

www.prostatecancerdecision.org or 800-249-0314

Information not specific to prostate cancer

American Society of Clinical Oncology People Living With Cancer: www.plwc.org (888-651-3038)

CDC Survivorship: www.cdc.gov/cancer/survivorship/index.htm

Lance Armstrong Foundation: www.livestrong.org

National Association for Home Care and Hospice: www.nahc.org (202-547-7424)

National Cancer Institute, Facing Forward survivor series: Life after cancer treatment. (1996); Ways you can make a difference in cancer (2002); guides for health professionals and family members (2003), reprinted 2004, Bethesda, MD.

National Hospice and Palliative Care Organization: www.nhpco.org (800-658-8898)

Clinical Trials Information

Coalition of National Cancer Cooperative Groups: www.CancerTrialsHelp.org (877-520-4457)

National Cancer Institute: www.cancer.gov/clinicaltrials (800-422-6237)

Appendix D: Prostate Cancer Advisory Committee

Primary/Secondary Prevention Workgroup

Willie Underwood, MD, MS *Chair*
Department of Urology
University of Michigan

Glenn Copeland, MBA
Director of Michigan Cancer Surveillance
Michigan Department of Community Health

Laurie DeDecker, RN
Michigan Cancer Genetics Alliance
Michigan Department of Community Health

Ray Demers, MD, MPH
ACPC Co-Chair
CEO and Medical Director
Great Lakes Cancer Institute

Archilind Franklin
Director, Minority Health Education
Karmanos Cancer Institute

Evelyn Gladney, RN
Ingham Regional Medical Center

Marc Keshishian, MD, MPH
Vice President and Chief Medical Officer, Clinical Affairs
Blue Care Network

Robert Knobel, P.E.
Prostate Cancer Support Group
Beaumont Hospital

Joan Long, RN
Grand Rapids Community Oncology Program

Isaac Powell, MD
Department of Urology
Wayne State University

Treatment Workgroup

Angela Fagerlin, PhD Chair

Department of Medicine
Ann Arbor VAMC and University of Michigan

Maha Hussain, MD

Departments of Medicine and Urology
University of Michigan

Michael Rice

Chair, Prostate Cancer Coalition of Michigan

David Rovner, MD

Department of Endocrinology
Michigan State University

Howard Sandler, MD

Department of Radiation Oncology
University of Michigan

Connie Szczepanek, RN, BSN

Director, Grand Rapids Community Oncology Program

John Wei, MD, MS

Department of Urology
University of Michigan

David Wood, MD

ACPC Co-Chair
Department of Urology
University of Michigan

Survivorship Workgroup

Laurel Northouse, RN, MSN, PhD Chair

School of Nursing
University of Michigan

Deb Dillingham

Director, Quality of Life
Great Lakes Division American Cancer Society

Margaret Holmes-Rovner, PhD

Center for Ethics & Humanities in the Life Sciences and Department of Medicine
Michigan State University

Lonnie Johnson, MSW, CSW
Prostate Cancer Coalition of Michigan

Claudia Parcels, MSN, FNP-BC

Jerry Sims
Prostate Cancer Coalition of Michigan

Consultants

Cathryn Bock, PhD
Karmanos Cancer Institute
Wayne State University

Richard Wimberley
Manager, Cancer Control Services Program
Michigan Public Health Institute

May Yassine, PhD
Senior Research Scientist/Epidemiologist
Michigan Public Health Institute

Staff

Carol Garlinghouse, MSN, RN
Nurse Consultant
Michigan Public Health Institute

Debra Kimball, MSN, RN
Nurse Consultant
Michigan Department of Community Health

Judi Suess, MD, MPH
Prostate Cancer Project Coordinator
Michigan Public Health Institute

Appendix E:

Selected Data from
The Cancer Burden in Michigan:
Selected Statistics

*Developed by the Michigan Public Health Institute
in support of the Michigan Cancer Control Initiative*

December 2005

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Background

This Appendix describes the prostate cancer burden in Michigan.

Disease Burden:

The first section of the Appendix presents the findings of epidemiological analyses of prostate cancer mortality and incidence. Population-wide data on prostate cancer cases and deaths due to cancer in 2001 and 2002 were made available from the statewide cancer registry at the Michigan Department of Community Health (MDCH). Age-adjusted mortality and incidence rates are presented. These were calculated by the direct age-adjustment method, using the 2000 U.S. population age distribution as the standard population, to allow comparisons across cancer sites and across population groups. Annual state population estimates based on actual size of the Michigan population, up to year 2001, were used in calculating rates. Comparisons of rates between gender and racial groups, and between the different geographical regions in the state, are presented. Michigan incidence and mortality rates for prostate cancer were compared to the corresponding national rates. National data were obtained from the Surveillance, Epidemiology, and End Results (SEER) program.¹

Data on stage at diagnosis of the prostate cancer cases that were reported in 2000 are presented. The proportions of cases diagnosed at different stages were compared between racial groups and between geographical regions to highlight disparities where they exist.

Changes that occurred in the incidence and mortality from prostate cancer in Michigan over a 15-year period are illustrated.

In March 1998, the American Cancer Society, the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention reported the average annual percent changes² in incidence and mortality for cancer in the United States during 1973-1990 and 1990-1995 as “A Report Card for the U.S.”³ on progress related to cancer prevention and control. Since 1985,

¹ A continuing program of the National Cancer Institute (NCI), the SEER program collects data on a routine basis from designated population-based cancer registries in various areas of the country. Trends in cancer incidence, mortality, and patient survival in the United States are derived from this database. SEER data are collected from nine geographic areas that represent an estimated 9.5 percent of the U.S. population. These areas include five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and four metropolitan areas (Detroit SMSA, Atlanta SMSA, San Francisco-Oakland SMSA, and Seattle-Puget Sound).

² The annual percent change (APC) in observed rates over a given time period is a measure used to assess overall past and projected trends related to cancer incidence and mortality. The APC was calculated using regression statistics described in the publication by Wingo, et al. The calculation of APCs assumes that the rates increased or decreased at a constant rate over the entire calendar year interval. A test of significance was done to determine whether the annual percent change was truly an estimate of a net change (i.e., difference observed is significantly different from zero).

³ Wingo, P.A., Ries, L.A.G., Rosenberg, H.M., Miller, D.S., Edwards, B.K. “Cancer Incidence and Mortality, 1973-1995. A Report Card for the U.S.” *Cancer*. March 12, 1998;1197-1207.

Michigan has been collecting similar data on new cases and deaths from specific cancers. Presented here are data illustrating the Michigan experience and a comparison of the U.S. and Michigan data for 1992-2001 for the five cancer sites included in the Michigan Cancer Control Initiative.

Relative Survival:

Michigan-specific data on rates of survival from the selected cancers are not available to us at this time. National SEER data on relative survival rates are presented. The relative survival rate represents the likelihood that a patient will not die from his or her cancer at some specified time (usually five years) after the initial cancer diagnosis.

Table 1.

Number of Prostate Cancer Deaths and
New Prostate Cancer Cases by *Age Group*,
Michigan 2002-03

	All Ages	Under 35	35-54	55-74	75 and Over
Deaths, 2003	985	0	18	265	702
New Cases, 2002	8,676	2	877	5,571	2,226

Table 2.

Prostate Cancer Incidence Rates,
Michigan 2002 vs. US 2002

	Number in Michigan	Age-Adjusted Rate*	
		Michigan (2002)	US-SEER (2002)
Total	8,676	195.0	176.3
Whites	6,768	171.8	171.9
Blacks	1,320	297.2	275.8

*Rate per 100,000 race- and gender-specific population.

Table 3.

Age-Specific Prostate Cancer Incidence Rates, Michigan 2002

	Number	Rate*
25-39 Years	6	0.6
40-49 Years	276	35.3
50-64 Years	2,986	378.4
65 Years and Over	5,408	1,059.7

*Rate per 100,000 age- and gender-specific population.

Table 4.

Numbers and Percentages of Invasive Prostate Cancer (Primary Site) by Stage at Diagnosis and *Race*, Michigan Residents, 2002

	Total Number	Stage at Diagnosis							
		Localized		Regional		Distant		Unknown	
		Number	%	Number	%	Number	%	Number	%
Total	8,677	6,951	80.1	700	8.1	192	2.2	834	9.6
Whites	6,768	5,429	80.2	597	8.8	131	1.9	611	9.0
Blacks	1,321	1,079	81.7	89	6.7	56	4.2	97	7.3

Table 5.

Prostate Cancer Mortality Rates, Michigan 2003 vs. US 2002

	Number in Michigan	Age-Adjusted Rate*	
		Michigan (2003)	US-SEER (2002)
Total	985	25.5	28.1
Whites	809	23.6	25.8
Blacks	169	44.7	63.0

*Rate per 100,000 race- and gender-specific population.

Table 6.

Black to White Ratio of Prostate Cancer Incidence and Mortality, Michigan 2001, 2002

Incidence Rate per 100,000 (2001)		Ratio Blacks/Whites
Blacks	Whites	
242.7	174.9	1.4
Mortality Rate per 100,000 (2002)		Ratio Blacks/Whites
Blacks	Whites	
47.2	25.2	1.9

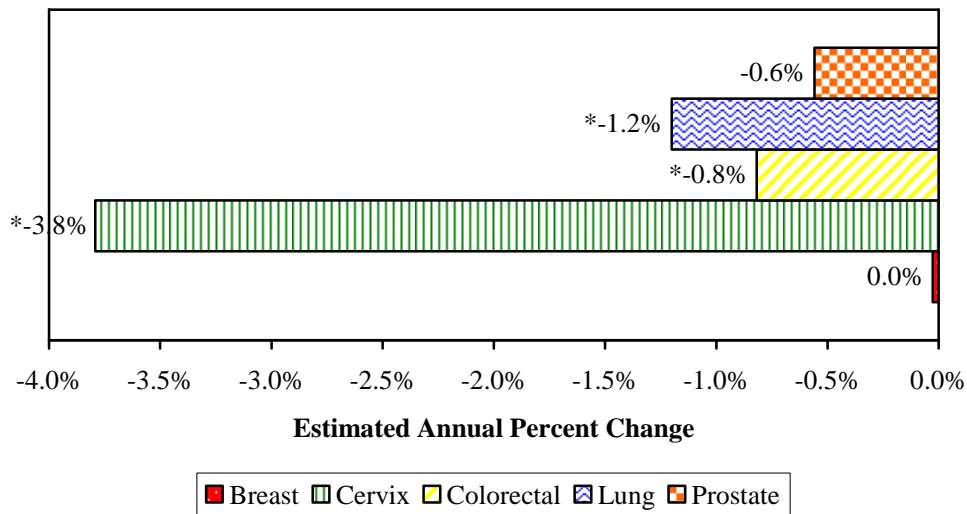
Table 7.

Prostate Cancer Five-Year Relative Survival Rates
by Stage at Diagnosis and *Race*, U.S. 1995-2001

	Total %	White %	Black %
All stages	99.8	99.9	96.7
Localized/Regional	100.0	100.0	100.0
Distant	33.5	32.6	30.3
Unknown	82.7	84.2	77.0

Chart 1.

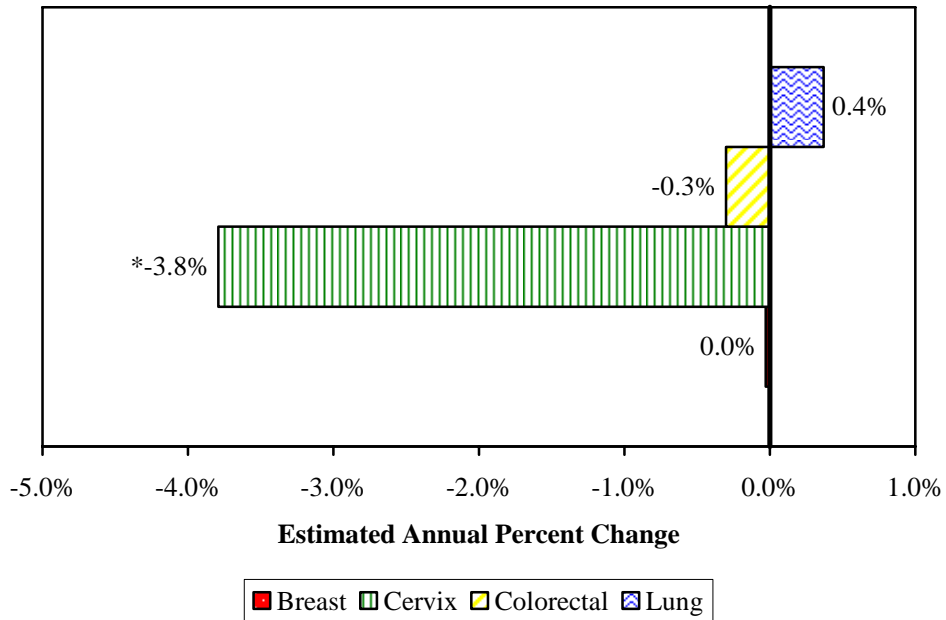
Estimated Annual Percent Change in Incidence Rates by Cancer Site, Michigan 1993-2002



* The EAPC is significantly different from zero ($p \leq .05$).
Rates are age-adjusted and computed by gender for breast, cervical and prostate cancer.

Chart 2.

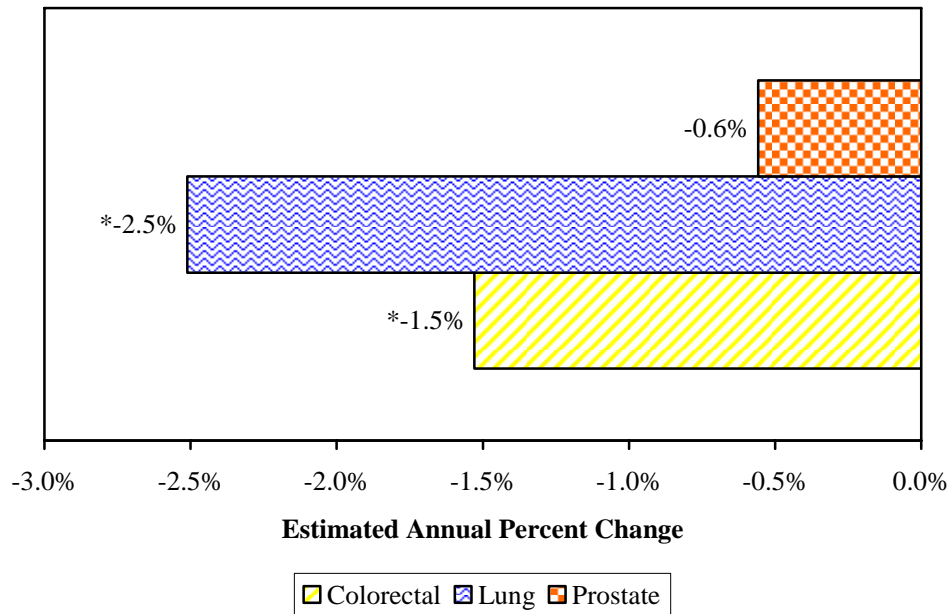
Estimated Annual Percent Change in Incidence Rates by Cancer Site, Michigan Females 1993-2002



* The EAPC is significantly different from zero ($p \leq .05$).
Rates are age-adjusted and computed by gender.

Chart 3.

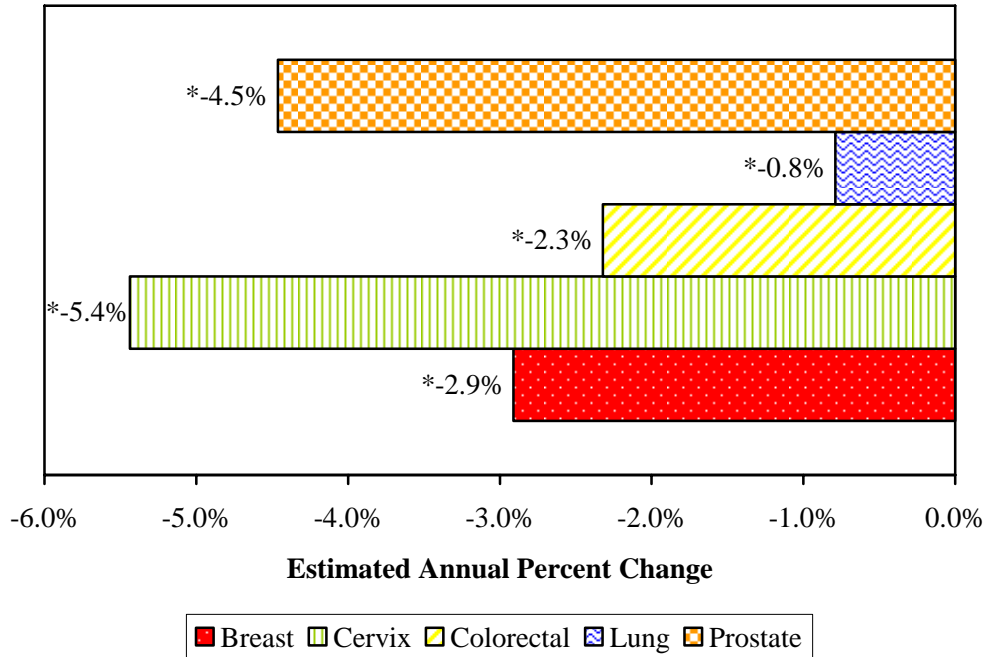
Estimated Annual Percent Change in Incidence Rates by Cancer Site, Michigan Males 1993-2002



* The EAPC is significantly different from zero ($p \leq .05$). Rates are age-adjusted and computed by gender.

Chart 4.

Estimated Annual Percent Change in Mortality Rates by Cancer Site, Michigan 1994-2003

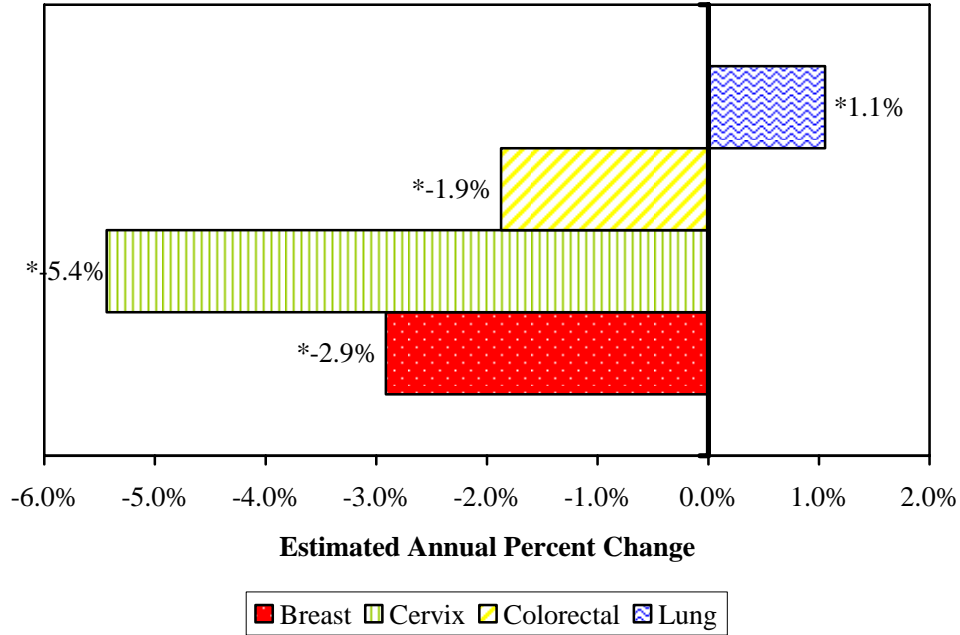


* The EAPC is significantly different from zero ($p \leq .05$).

Rates are age-adjusted and computed by gender for breast, cervical and prostate cancer.

Chart 5.

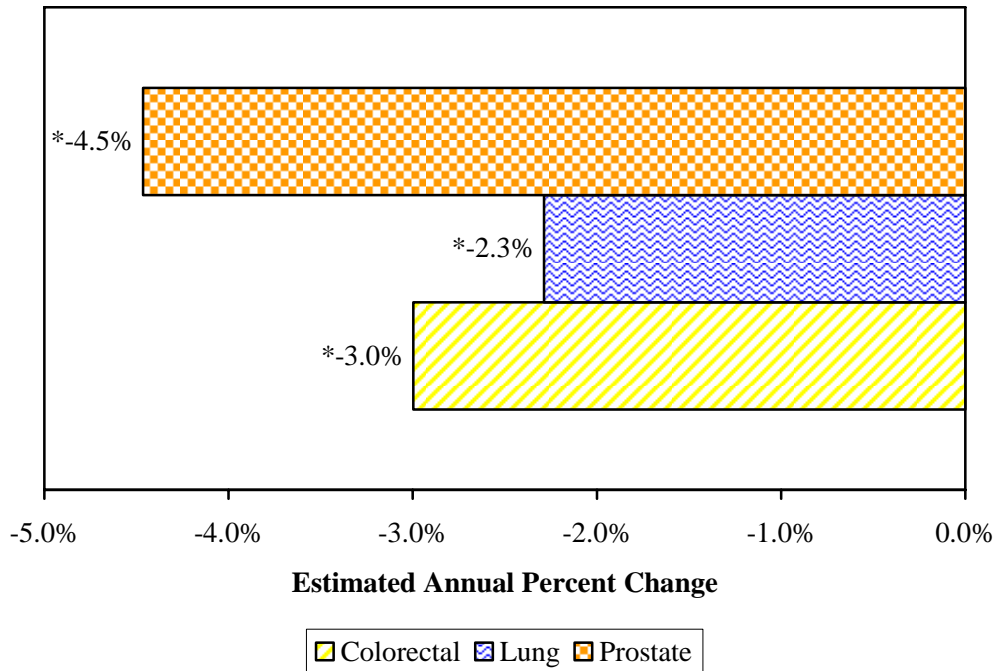
Estimated Annual Percent Change in Mortality Rates by Cancer Site, Michigan Females 1994-2003



* The EAPC is significantly different from zero ($p \leq .05$).
Rates are age-adjusted and computed by gender.

Chart 6.

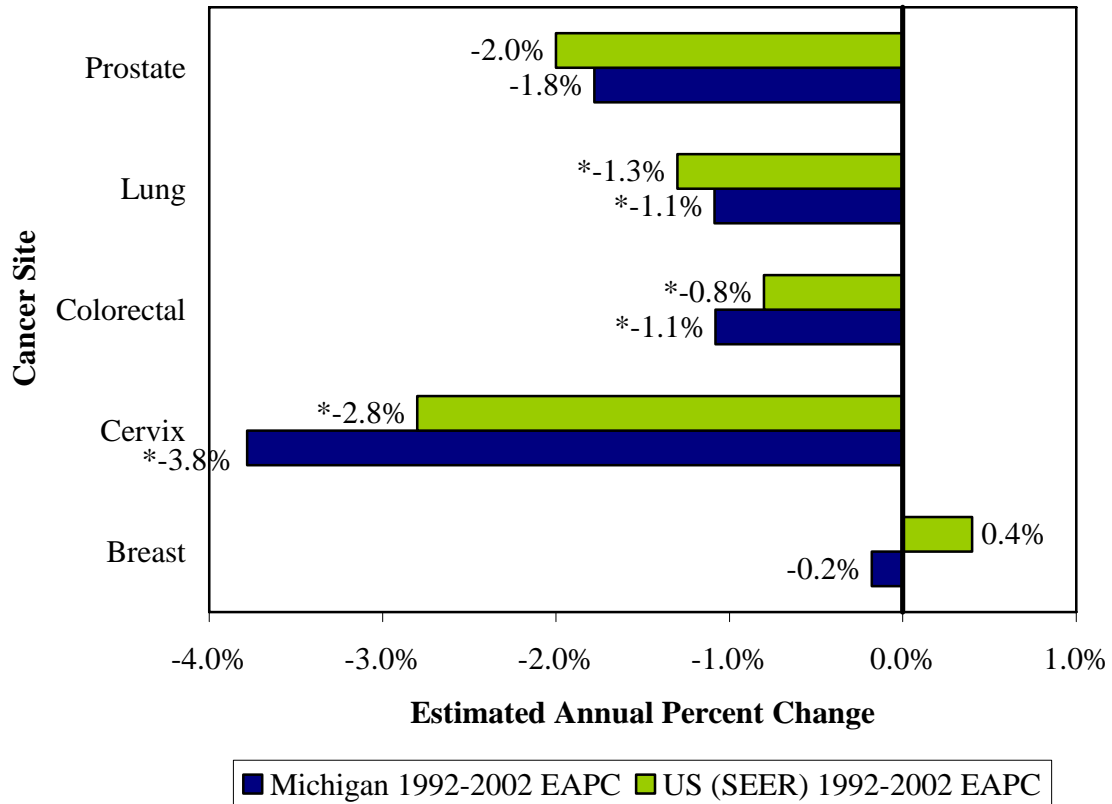
Estimated Annual Percent Change in Mortality Rates by Cancer Site, Michigan Males 1994-2003



* The EAPC is significantly different from zero ($p \leq .05$).
Rates are age-adjusted and computed by gender.

Chart 7.

Estimated Annual Percent Change in Incidence Rates, Michigan vs. US 1992-2002

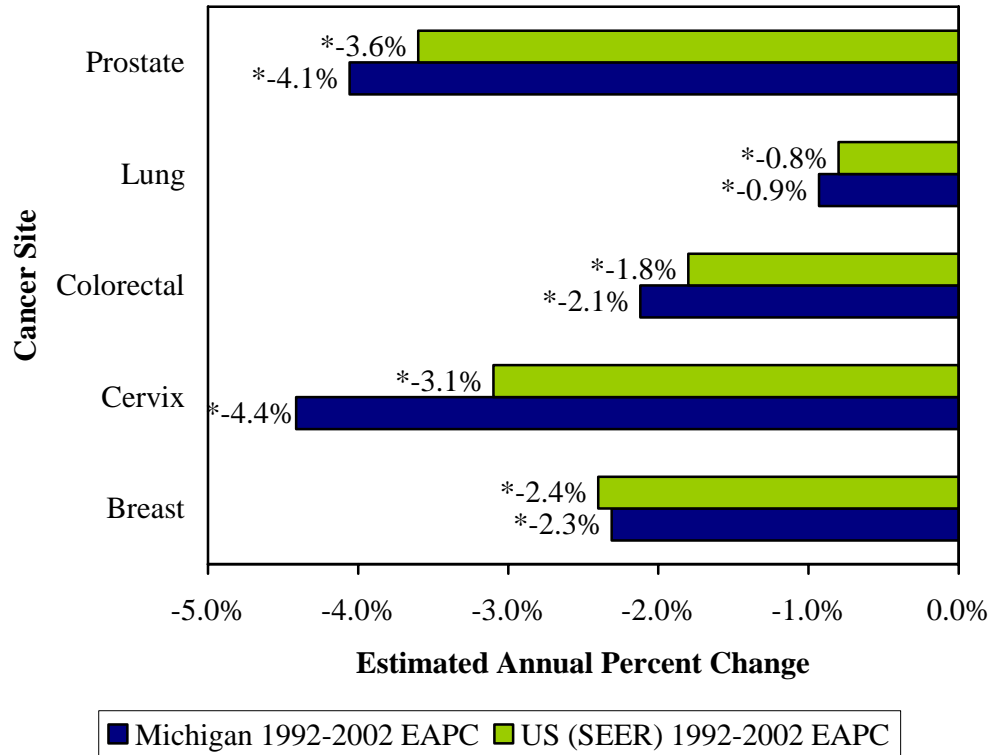


* The EAPC is significantly different from zero ($p \leq .05$).

Rates are age-adjusted and computed by gender for breast, cervical and prostate cancer.

Chart 8.

Estimated Annual Percent Change in Mortality Rates, Michigan vs. US 1992-2002

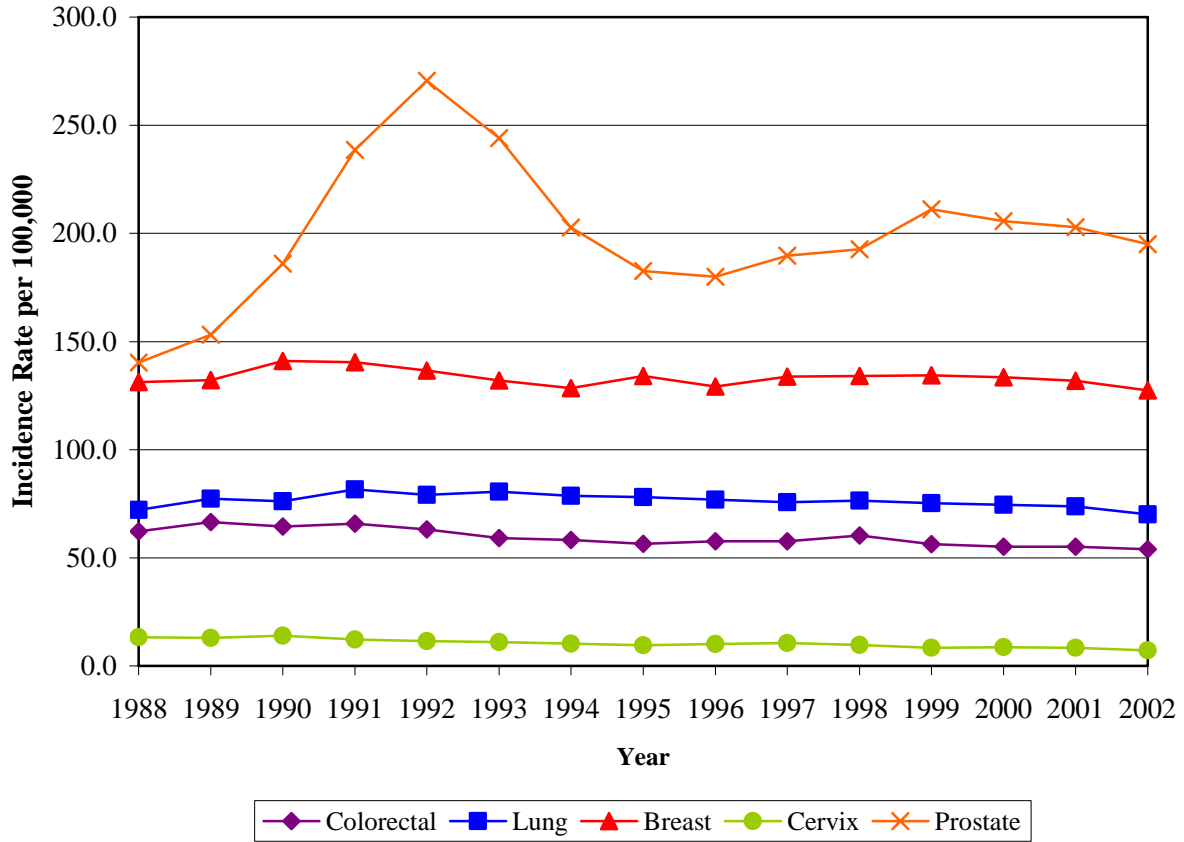


* The EAPC is significantly different from zero ($p \leq .05$).

Rates are age-adjusted and computed by gender breast, cervical and prostate cancer.

Chart 9.

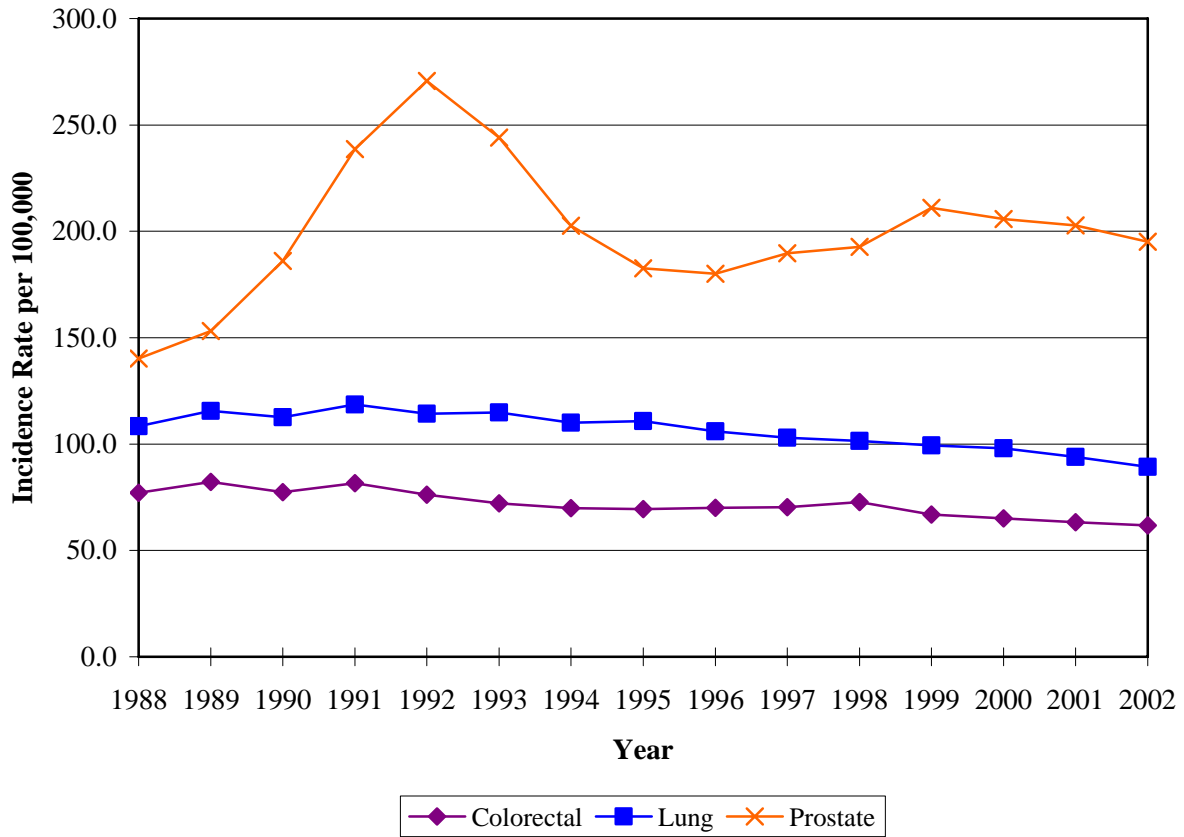
Total Incidence Rates by Cancer Site, Michigan 1988-2002



Rates are age-adjusted per 100,000 population and computed by gender for breast, cervical and prostate cancer.

Chart 10.

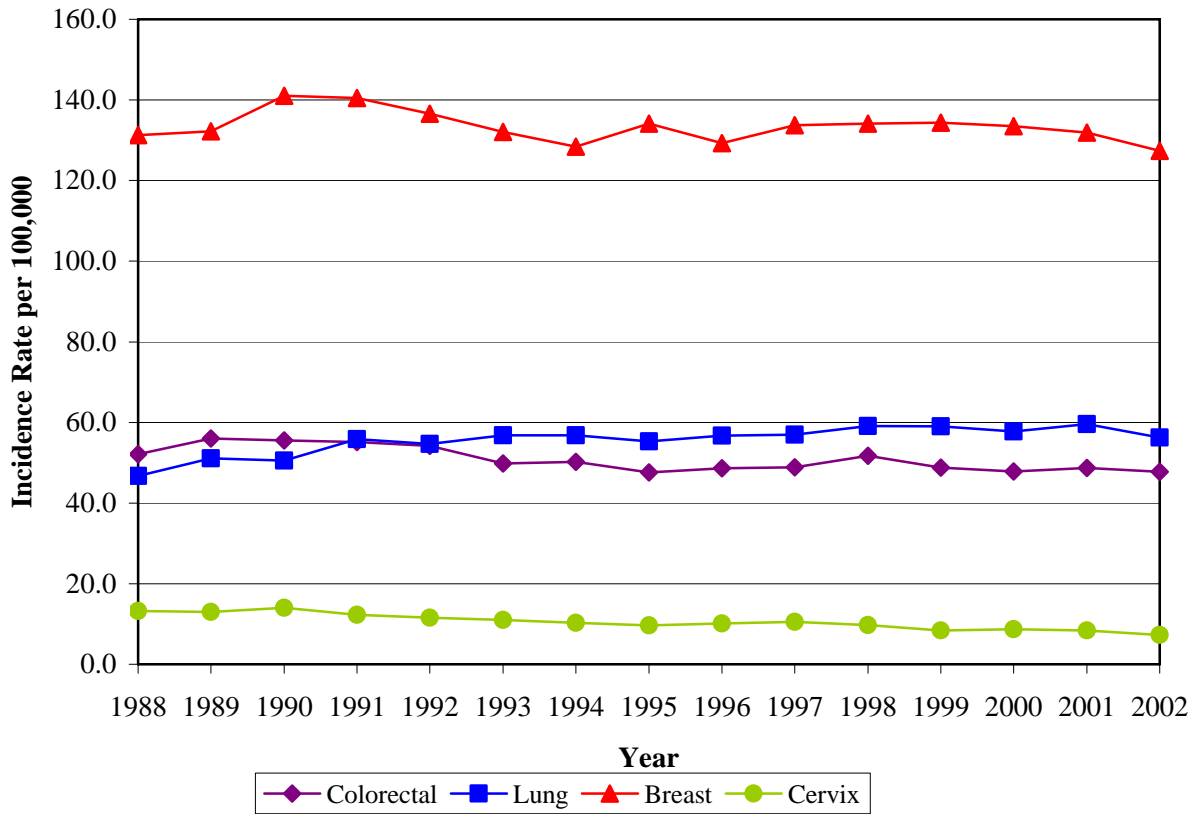
Male Incidence Rates by Cancer Site, Michigan 1988-2002



Rates are age-adjusted per 100,000 gender-specific population.

Chart 11.

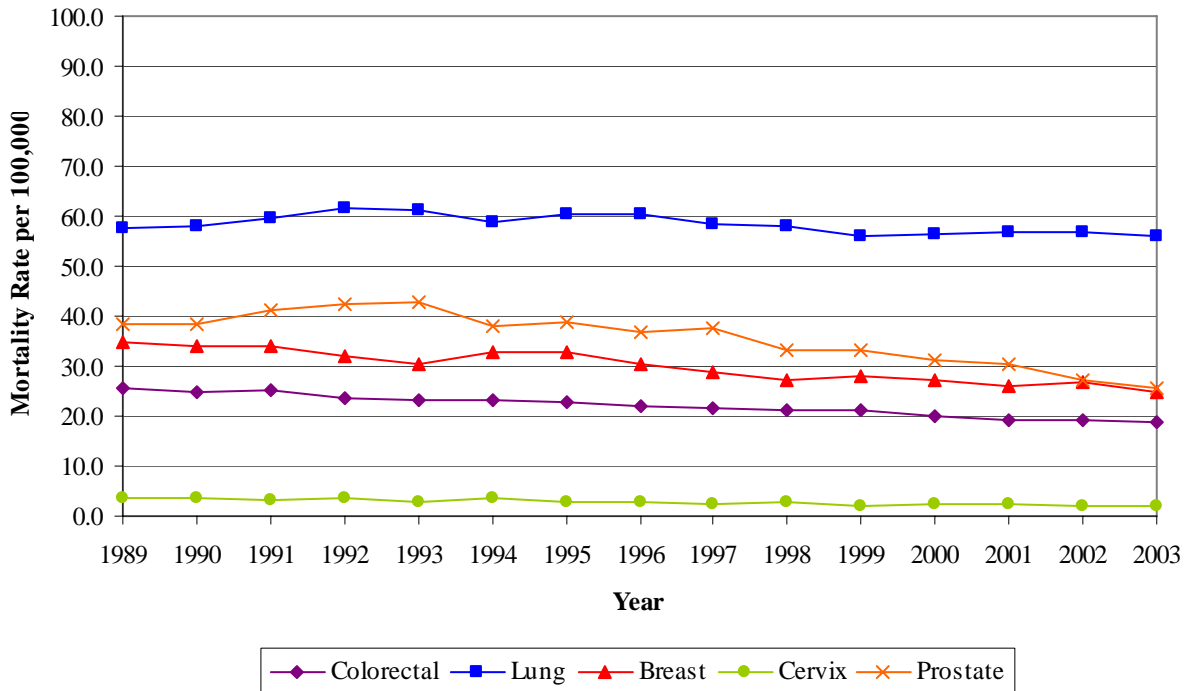
Female Incidence Rates by Cancer Site, Michigan 1988-2002



Rates are age-adjusted per 100,000 gender-specific population.

Chart 12.

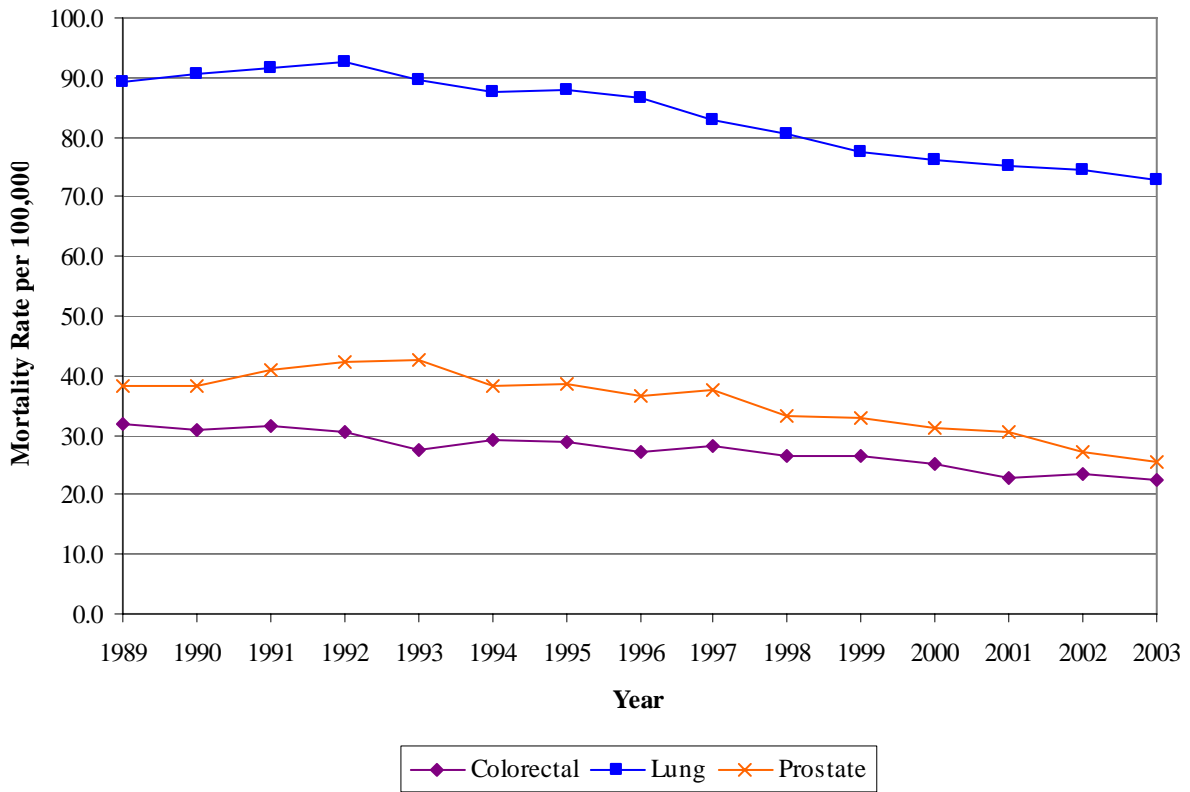
Total Mortality Rates by Cancer Site, Michigan 1989-2003



Rates are age-adjusted per 100,000 population and computed by gender for breast, cervical and prostate cancer.

Chart 13.

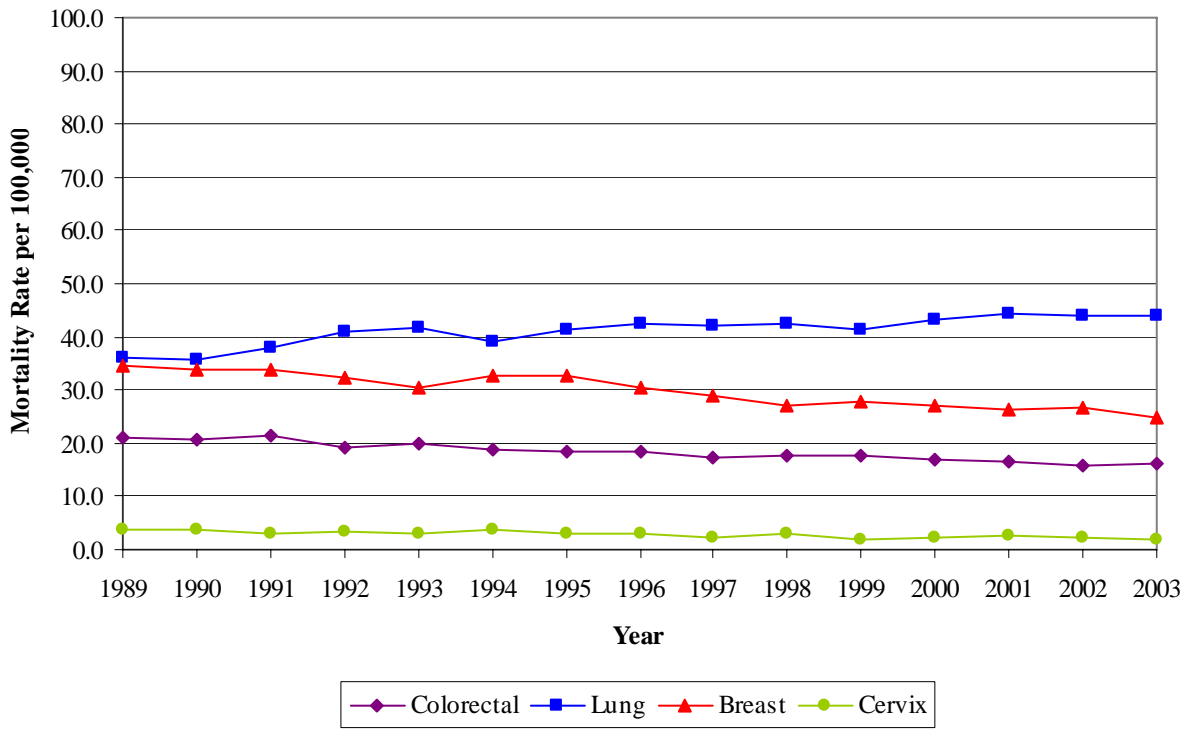
Male Mortality Rates by Cancer Site, Michigan 1989-2003



Rates are age-adjusted per 100,000 gender-specific population.

Chart 14.

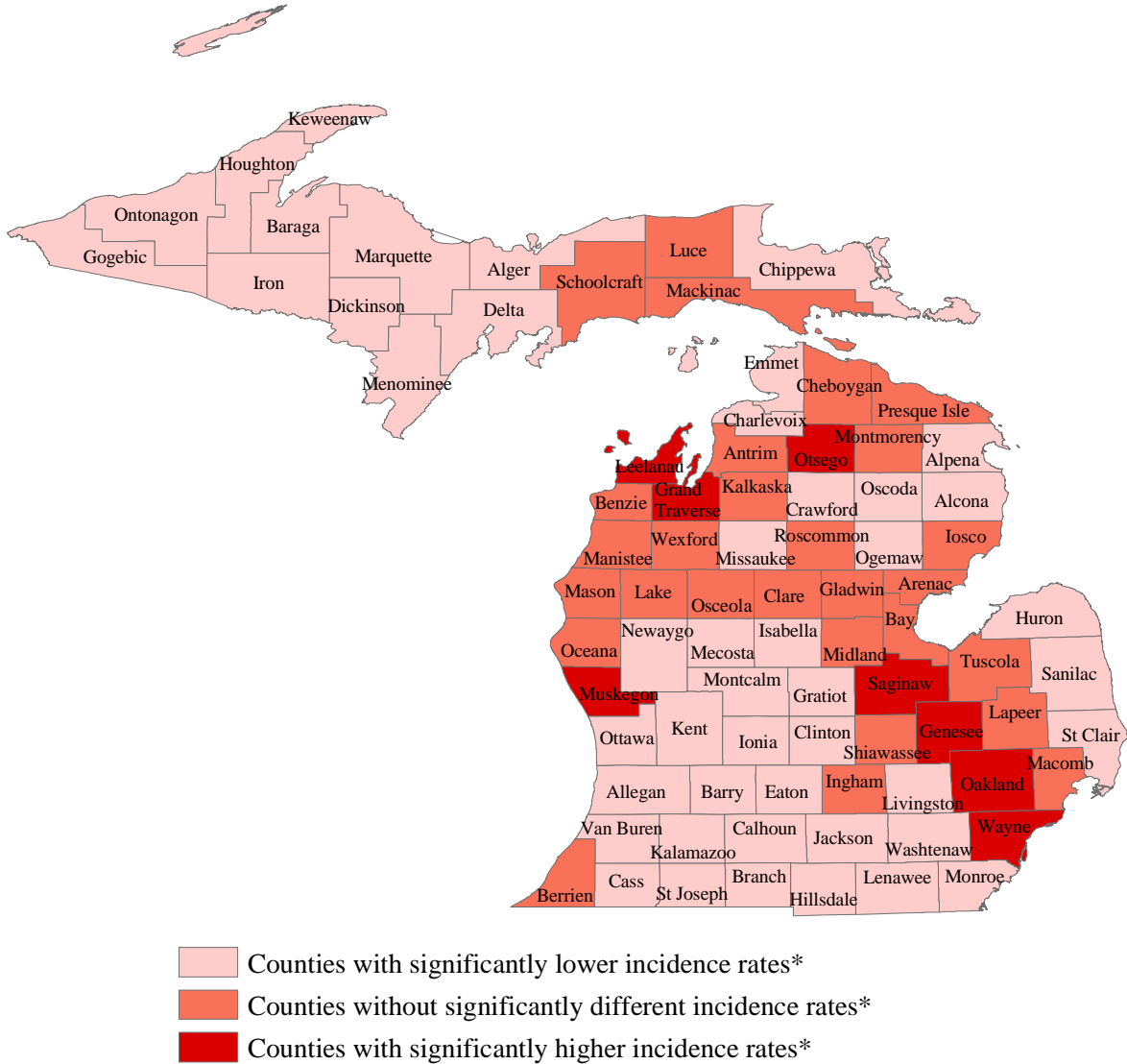
Female Mortality Rates by Cancer Site, Michigan 1989-2003



Rates are age-adjusted per 100,000 gender-specific population.

Figure 1.

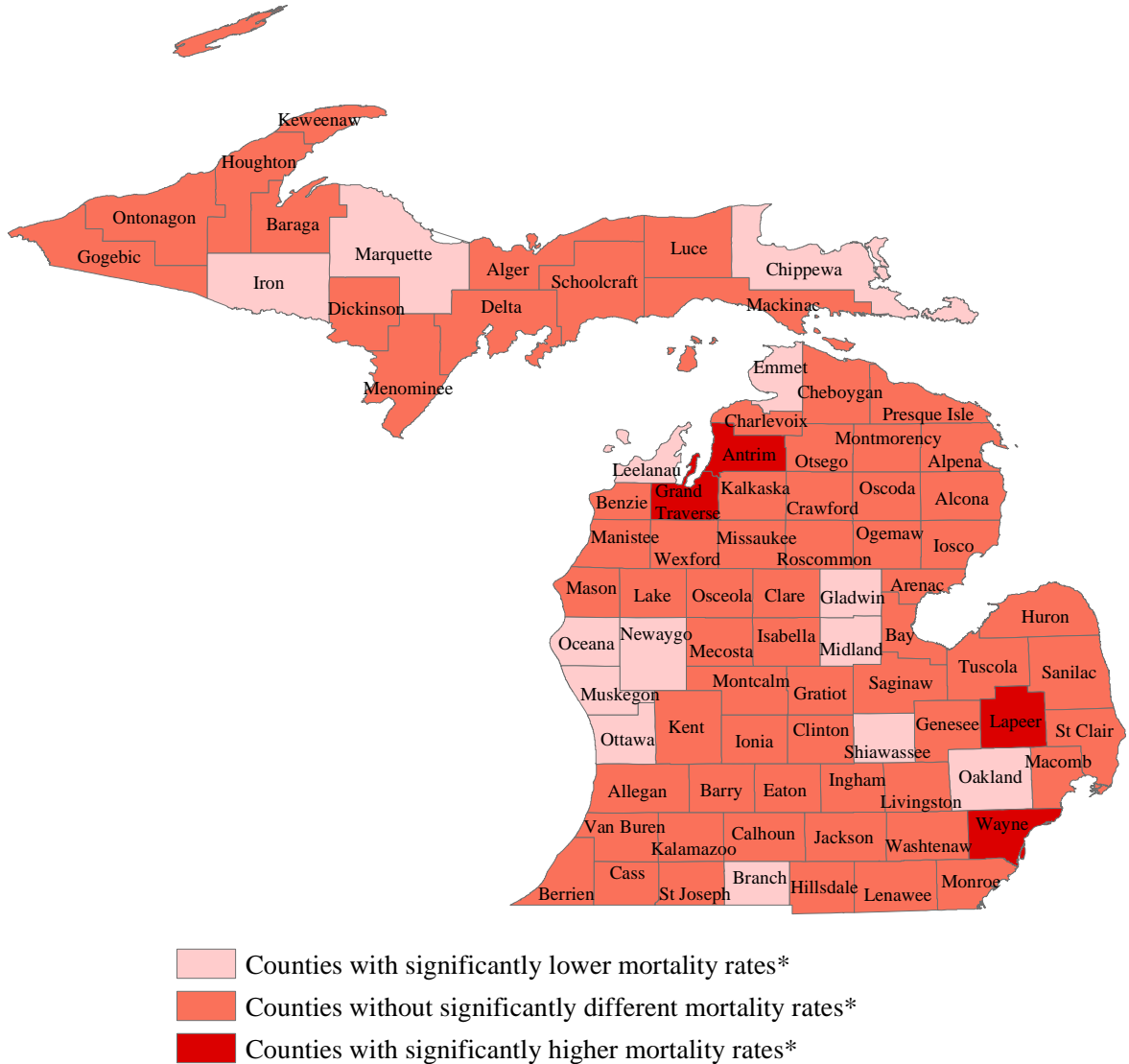
Prostate Cancer Incidence Rates by County, 1993-2002



*Differences in age-adjusted incidence rates were statistically tested at 95% confidence levels to compare each county with the all-county rate.

Figure 2.

Prostate Cancer Mortality Rates by County, 1994-2003



*Differences in age-adjusted mortality rates were statistically tested at 95% confidence levels to compare each county with the all-county rate.

Appendix F:
Cost of Cancer

*Developed by the Michigan Public Health Institute
in support of the Michigan Cancer Control Initiative*

December 2004

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Introduction

I. Years of life lost

Mortality and survival rates give an incomplete picture of the burden of cancer deaths in a population, so years of life lost (YLL) due to premature death from cancer was calculated to add another dimension to the description of burden. Person-years of life lost (PYLL) were calculated for this report as follows: For each of the individuals who died of a particular cancer, it was possible to obtain the number of years they would have been expected to live had they not died of cancer for that individual's gender and/or race, conditional on their survival to the age at which they died of cancer. Life expectancy data were obtained from the National Center for Health Statistics (NCHS). The ages used in the calculation were in five-year groups with the remaining years of life averaged over the five ages within each age interval. These YLL's were then summed over all deaths due to cancer for each of the sites to get the estimate of PYLL. Also presented is the average years of life lost (AYLL), calculated by dividing the PYLL by the total number of deaths.

Estimates of the other human costs are scant. For the cancer patient, morbidity indicators, loss of work or school time, and periods of restricted activity due to the disease or its treatment are difficult to measure. In addition, there are significant human and financial costs to family members and other care givers who give up activities, opportunities, and income to provide assistance to cancer patients. To date, we have not identified such data for the cancers of interest here.

II. Financial cost of cancer

Cancer accounts for a large portion of health care expenditures when both direct and indirect costs are combined, therefore constituting a significant proportion of this burden to the United States. The available information on financial cost of cancer in Michigan is far from complete. Included in this report is information on expenditures in a given year for Medicare (part A) and Blue Cross & Blue Shield (BCBS) of Michigan. Self-insured plans that are administered by BCBS are included in the BCBS data presented; however, *in situ* cancer diagnoses are excluded from this data set. Also presented is Michigan-specific hospitalization information that was obtained from the Michigan Department of Community Health Hospital Discharge Data System. This report includes information on the rates of discharges per year, rates of days of care per year, and average length of stay per year for prostate cancer, as well as additional selected cancer sites. *In situ* cases are included in the Medicare and the hospital discharge datasets. Data on financial cost are not for individuals tracked through the entire course of their illness. They represent the paid claims during a given year for all patients with the selected cancers, at various stages in the course of the disease. Cost data do not include out-of-pocket costs for deductibles, medications, etc.

Chart 1.

Total Person-Years of Life Lost Due to Cancer by Cancer Site, Michigan 2002

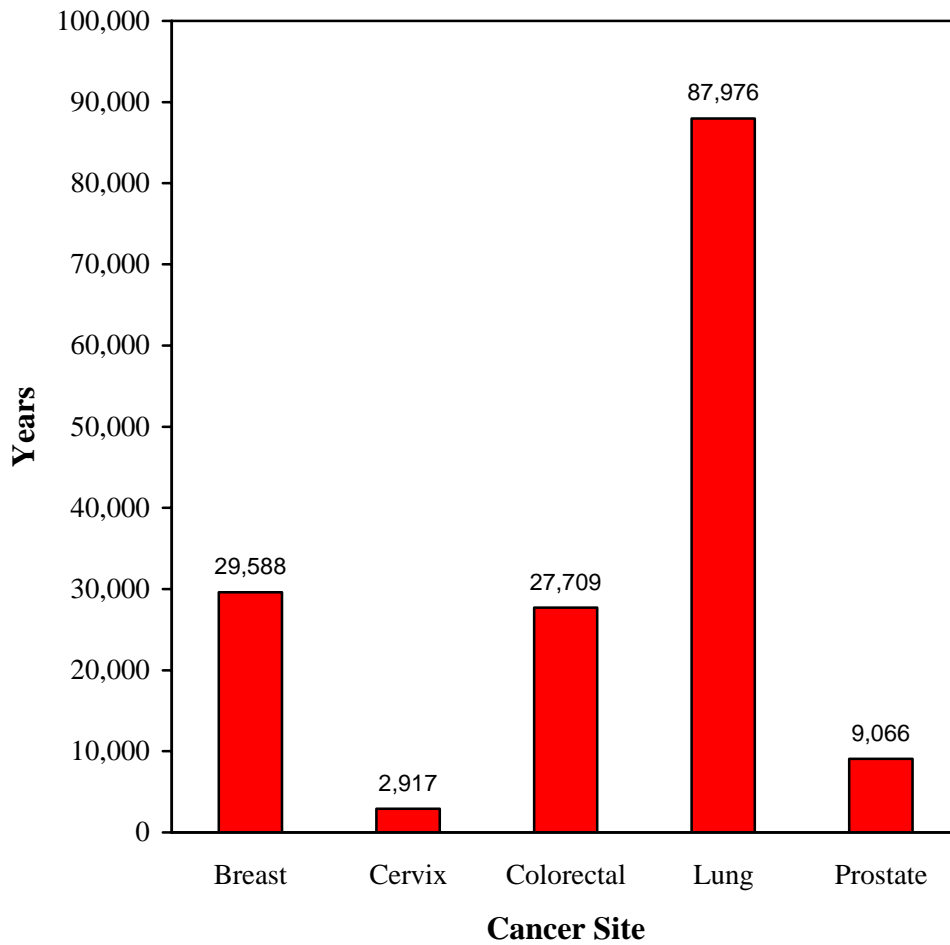


Chart 2.

Total Person-Years of Life Lost Due to Cancer, Michigan 1988-2002

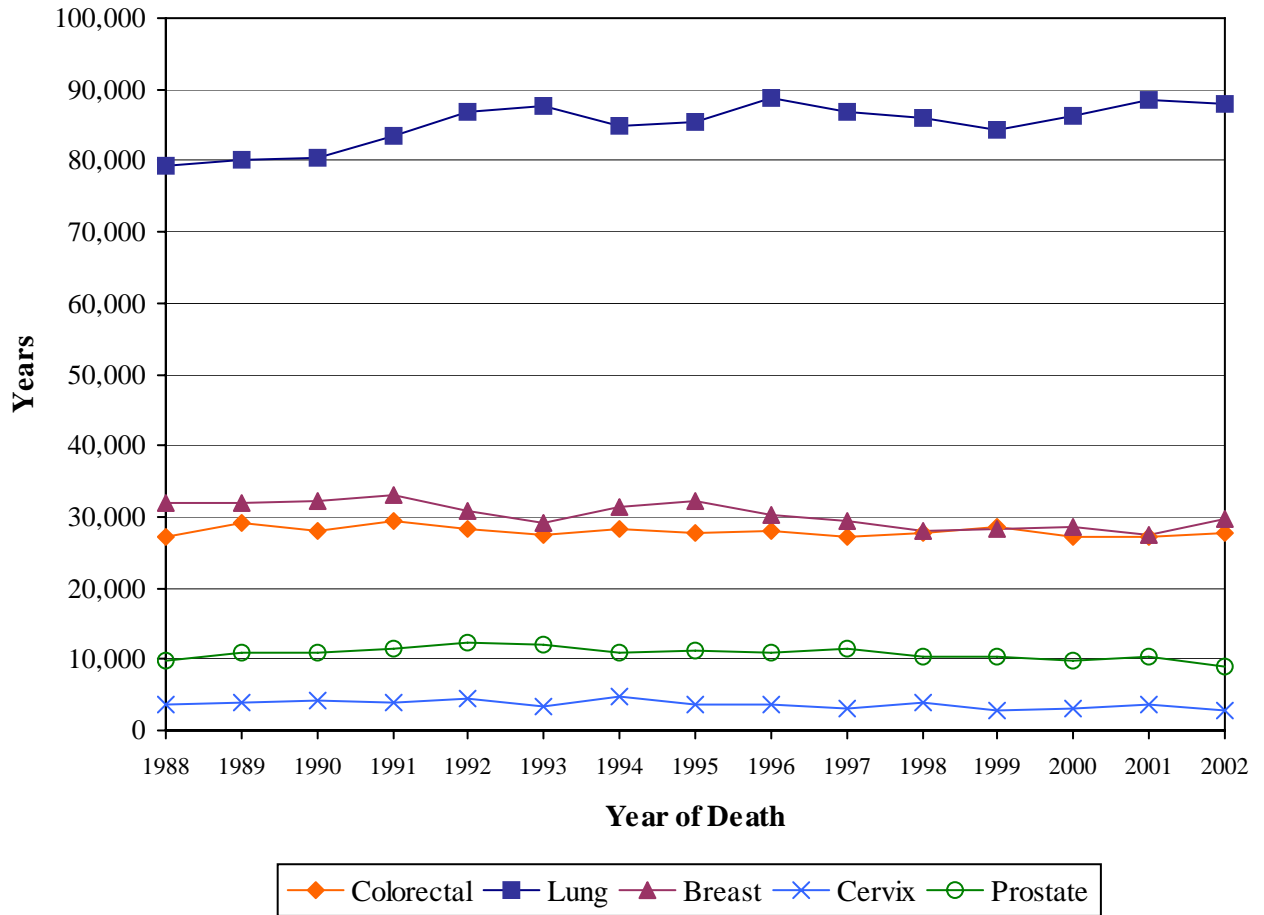


Chart 3.

Average Person-Years of Life Lost Due to Cancer, Michigan 1988-2002

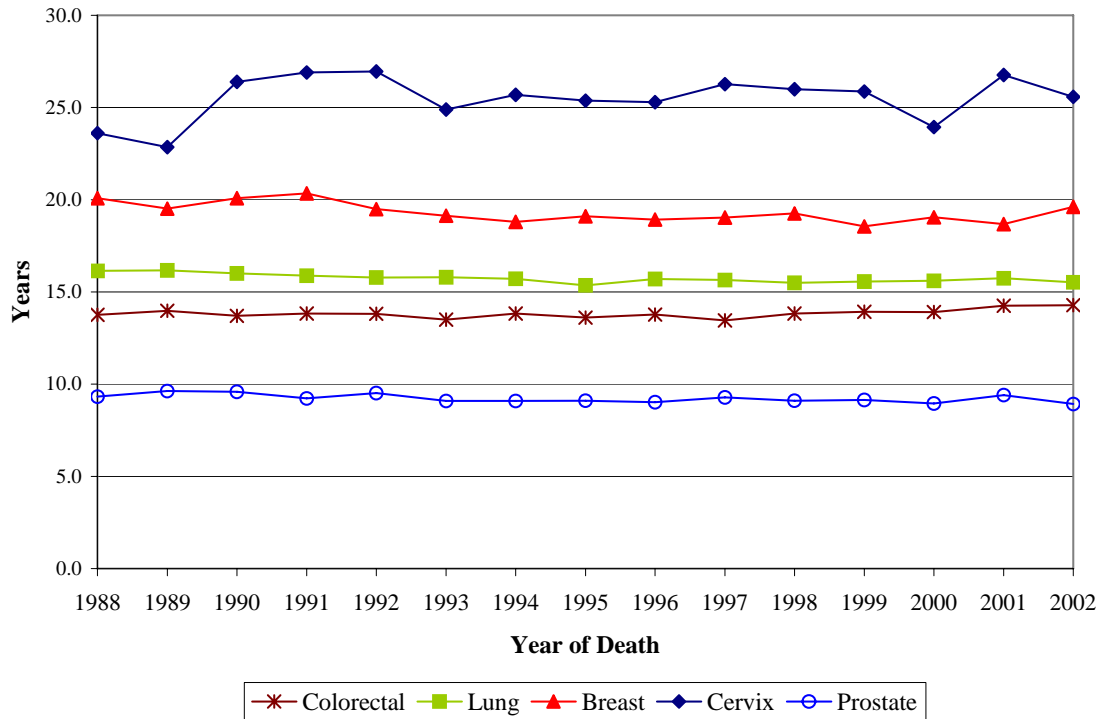


Chart 4.

Average Person-Years of Life Lost by Cancer Site and Race, Michigan 2002

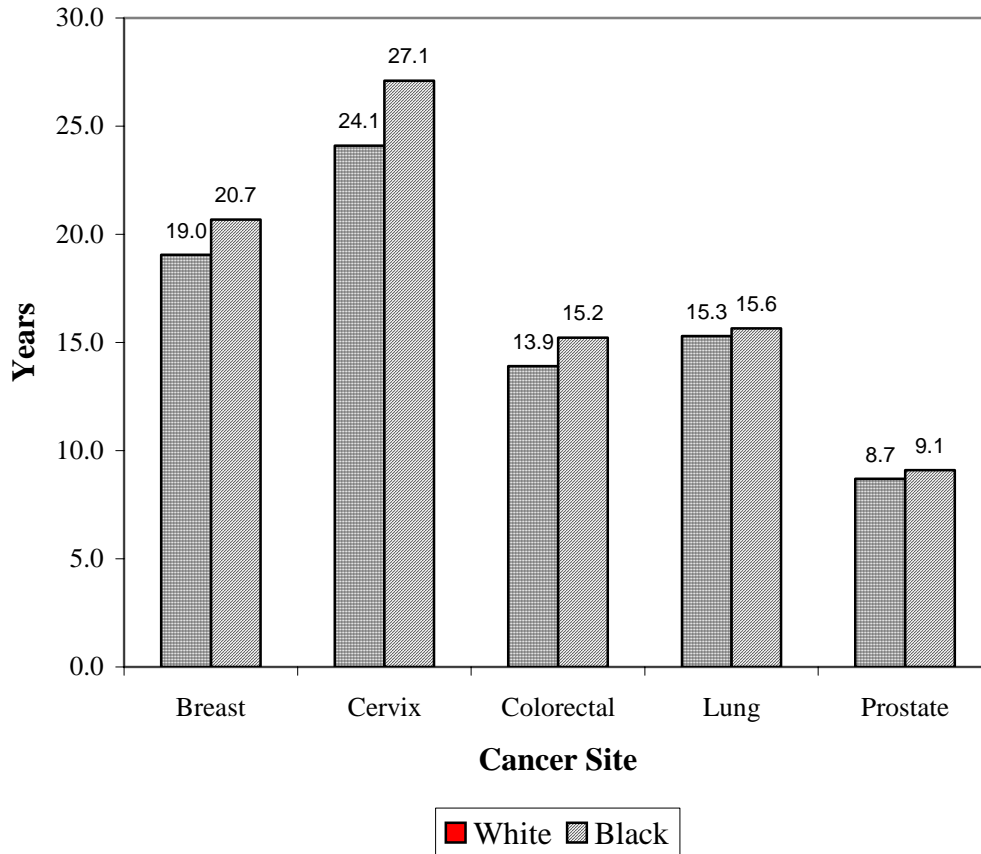
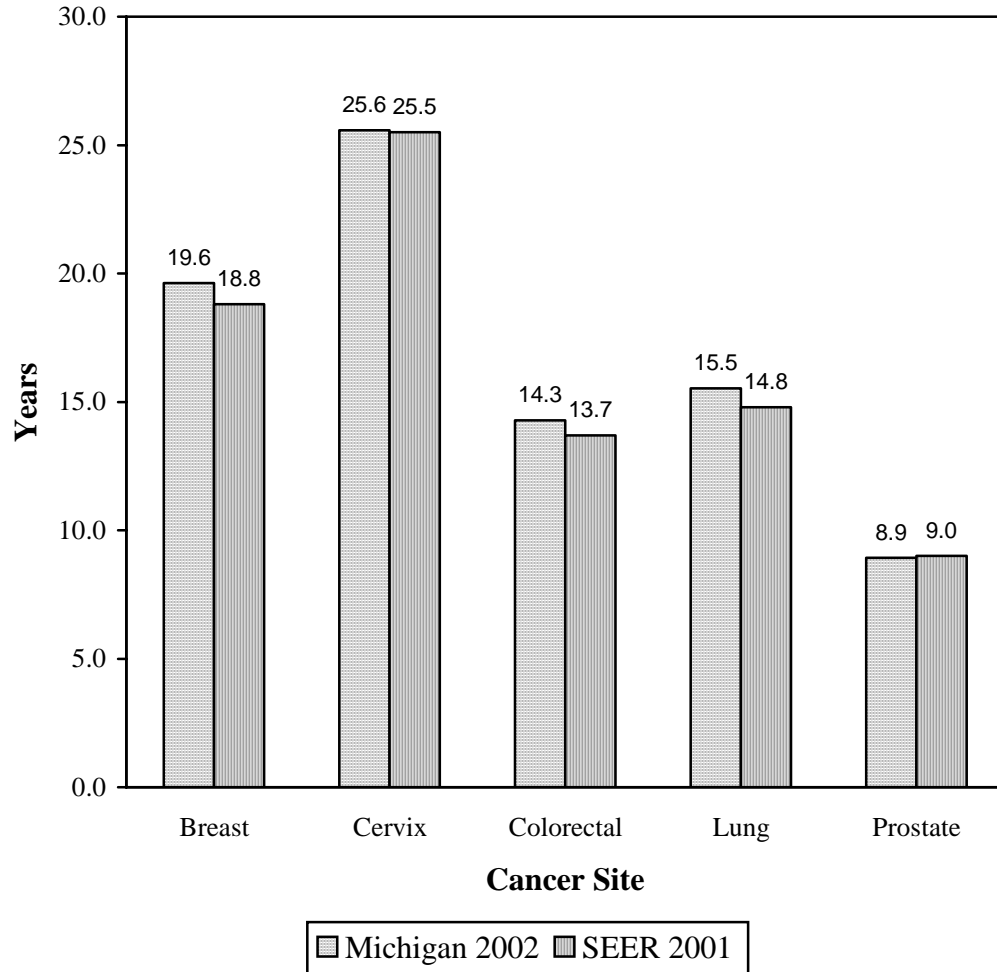


Chart 5.

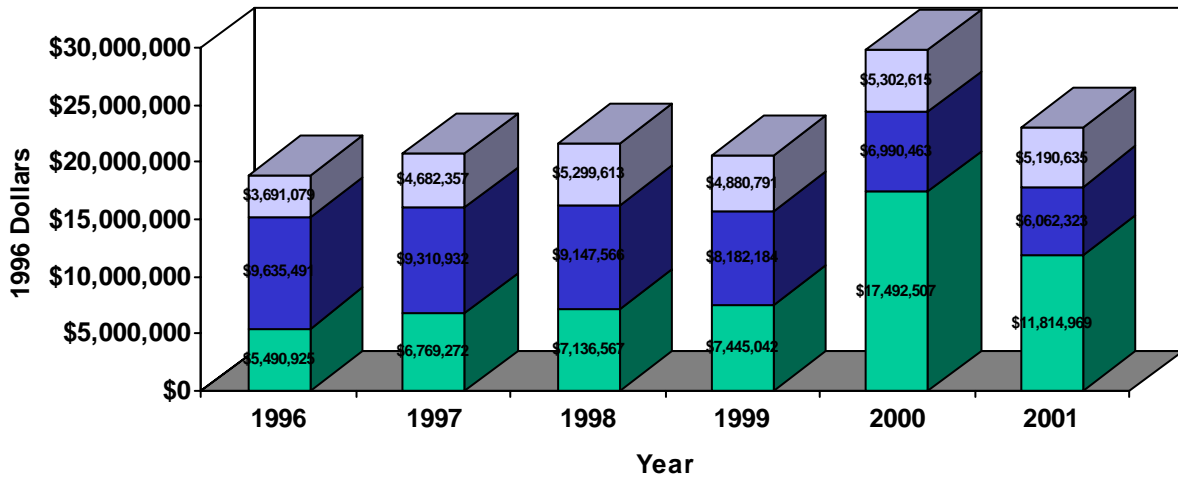
Average Person-Years of Life Lost by Cancer Site Michigan 2002 and SEER 2001



- SEER estimate of average years of life lost due to breast cancer includes both male and female deaths.

Chart 6.

Prostate Cancer Total BCBSM* Payments by Type of Claim (1996 – 2001)

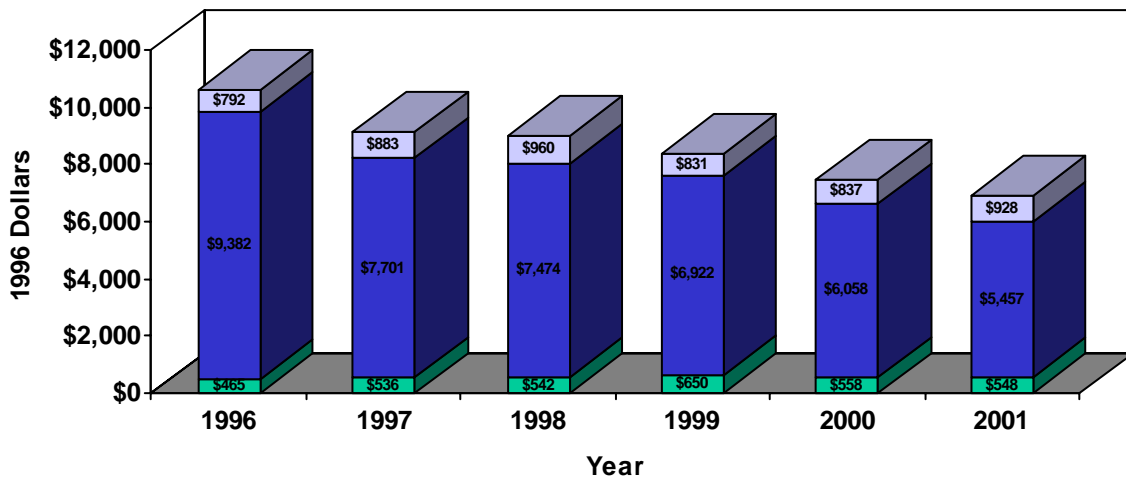


- **Outpatient Claims:** hospital billings for outpatient charges
- **Inpatient Claims:** hospital billings for inpatient charges
- **Professional Claims:** anything billed by physicians, labs, suppliers-NOT by facility providers (hospitals); includes inpatient physician professional services

*Excludes managed care plan.

Chart 7.

Prostate Cancer Per Case Average BCBSM* Payments by Type of Claim (1996 – 2001)



- Outpatient Claims: hospital billings for outpatient charges
- Inpatient Claims: hospital billings for inpatient charges
- Professional Claims: anything billed by physicians, labs, suppliers-NOT by facility providers (hospitals); includes inpatient physician professional services

*Excludes managed care plan.

Chart 8.

Prostate Cancer Total Medicare Part A Payments (1996 – 2001)

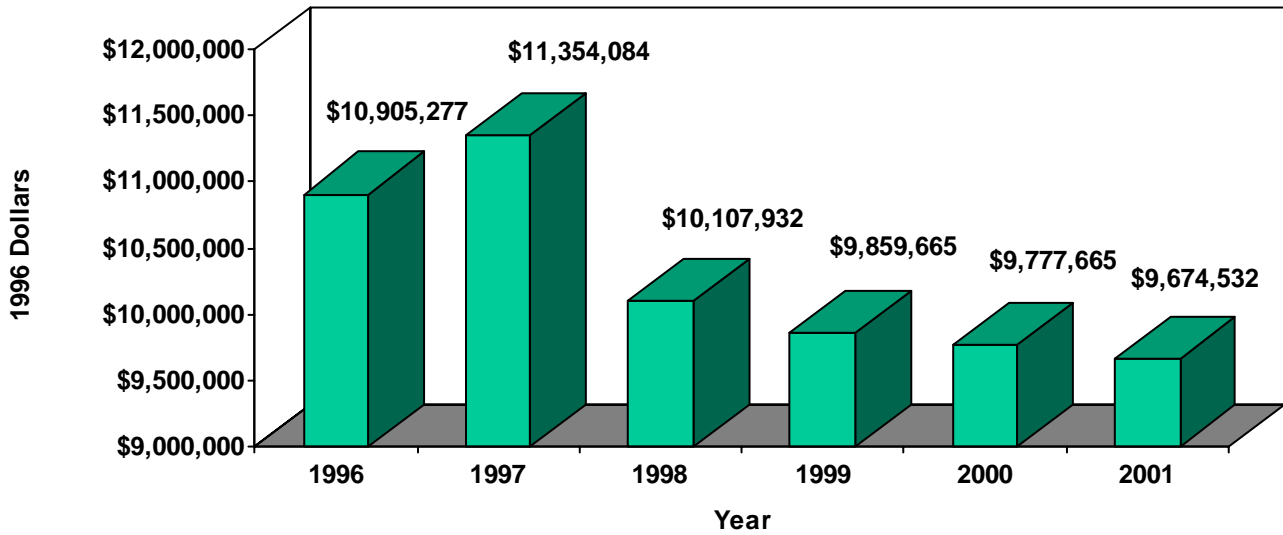


Chart 9.

Prostate Cancer per Case Average Medicare Part A Payments (1996 – 2001)

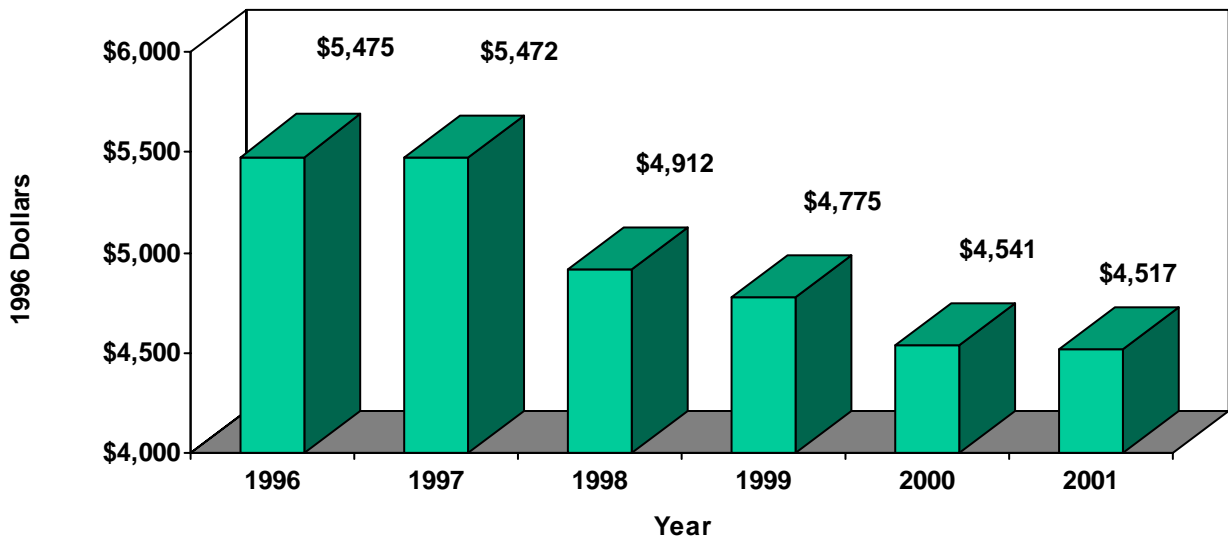


Chart 10.

Prostate Cancer Hospital Average Length of Stay for BCBSM* Inpatient Coverage Recipients (1996 – 2001)

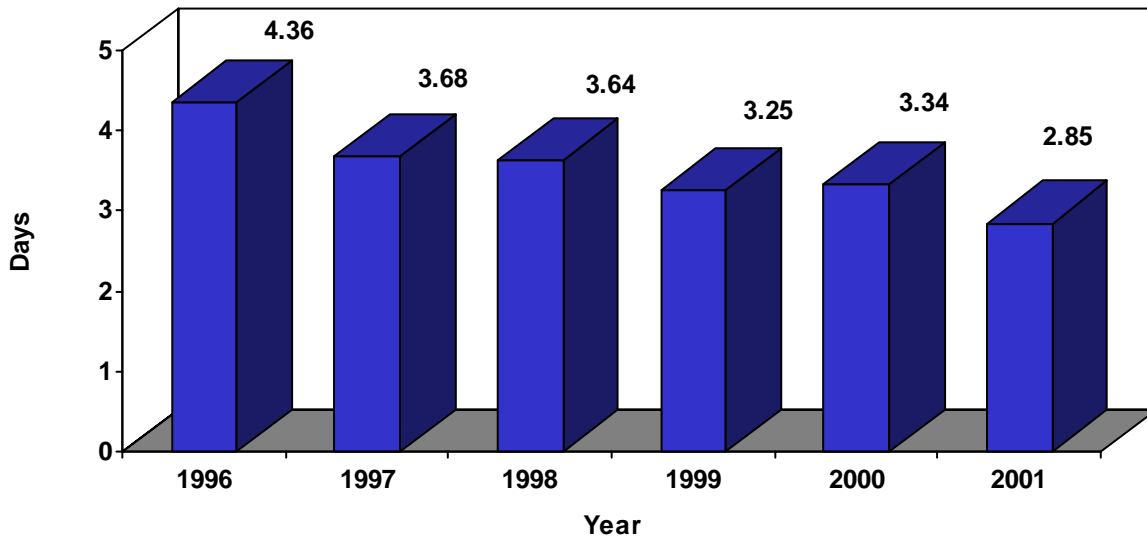


Chart 11.

Prostate Cancer Hospital Average Length of Stay for Medicare Part A Recipients (1996 – 2001)

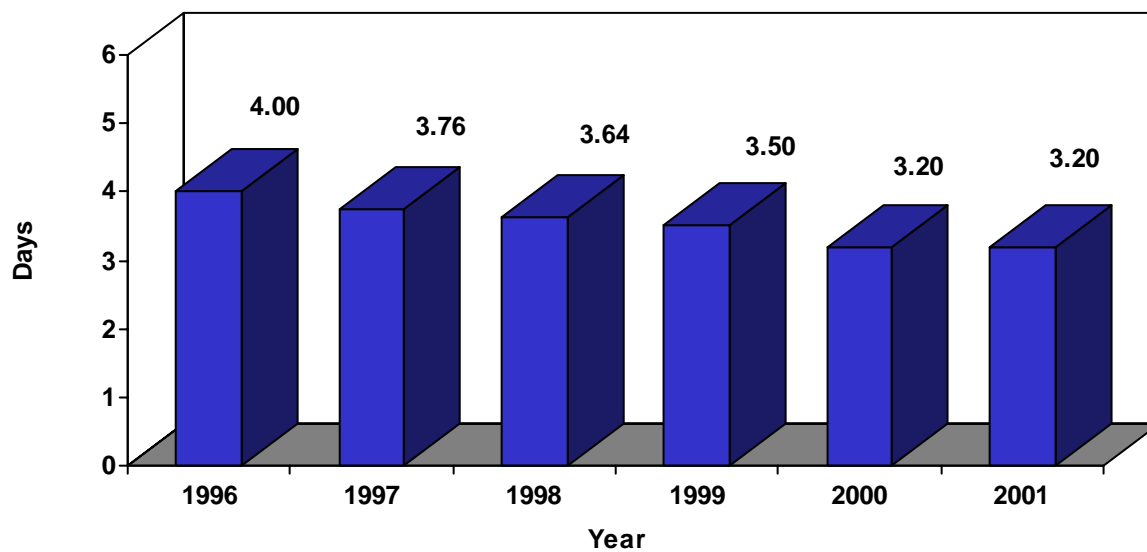


Chart 12.

Rates* of Hospital Days of Care by Cancer Site, Michigan 1991-2001

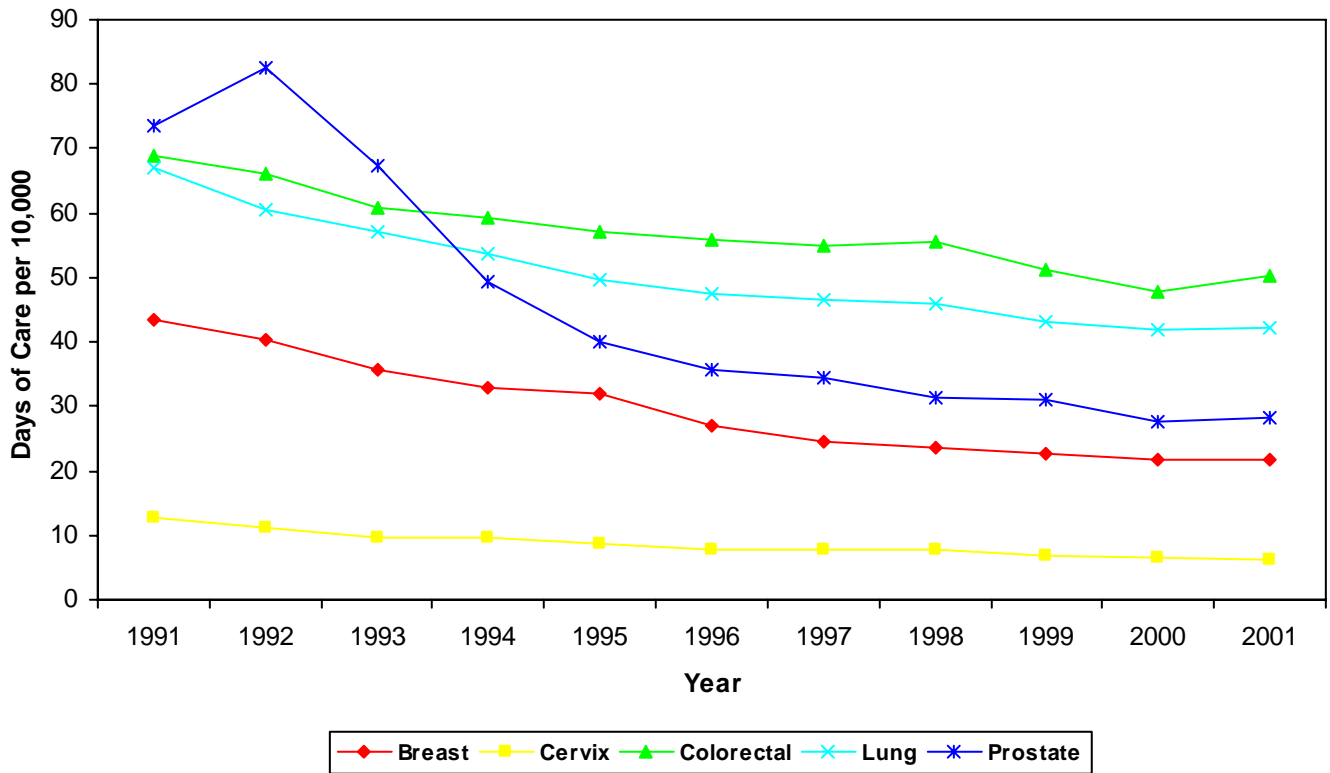


Chart 13.

Hospital Average Length of Stay by Cancer Site, Michigan 1991-2001

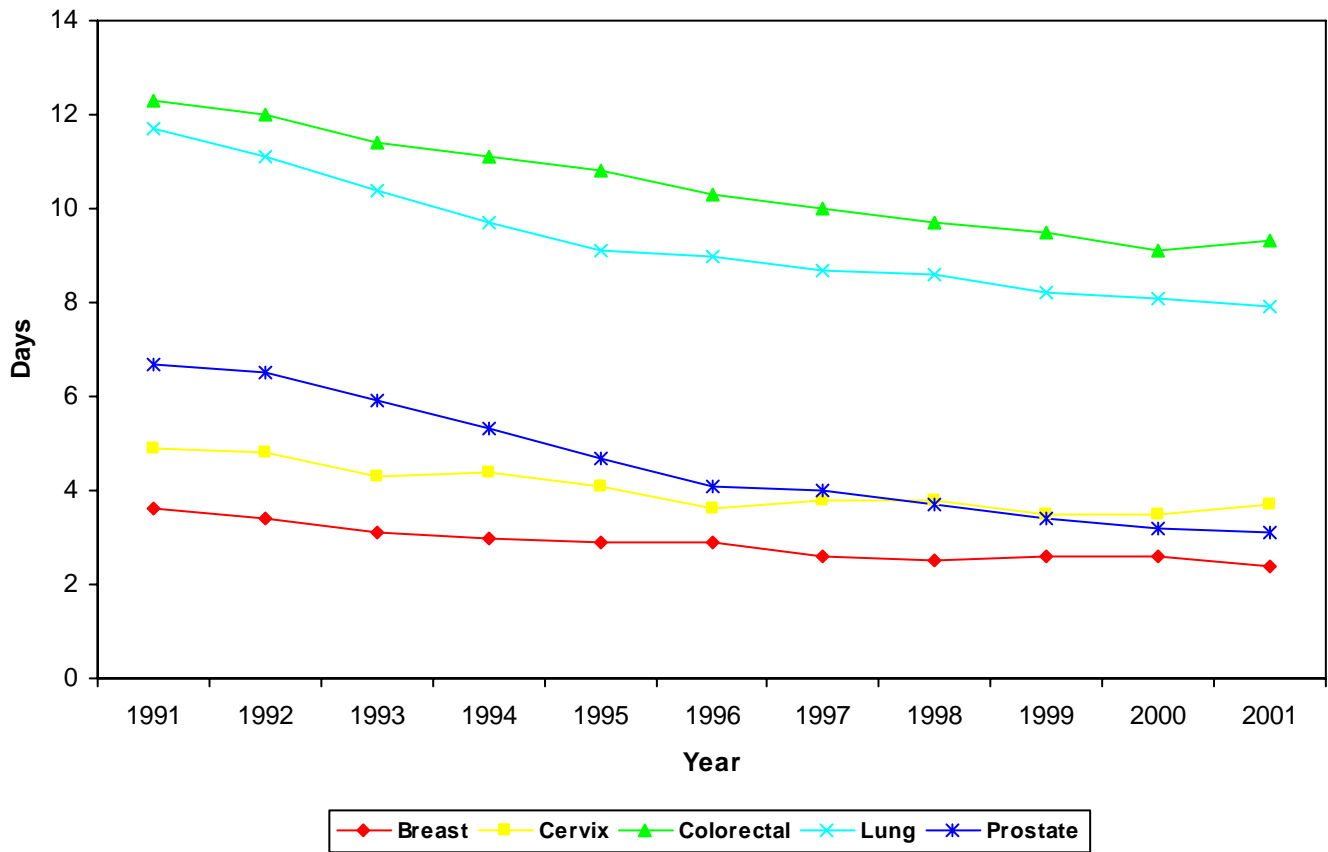


Chart 14.

Rates* of Hospital Discharge by Cancer Site, Michigan 1991-2001

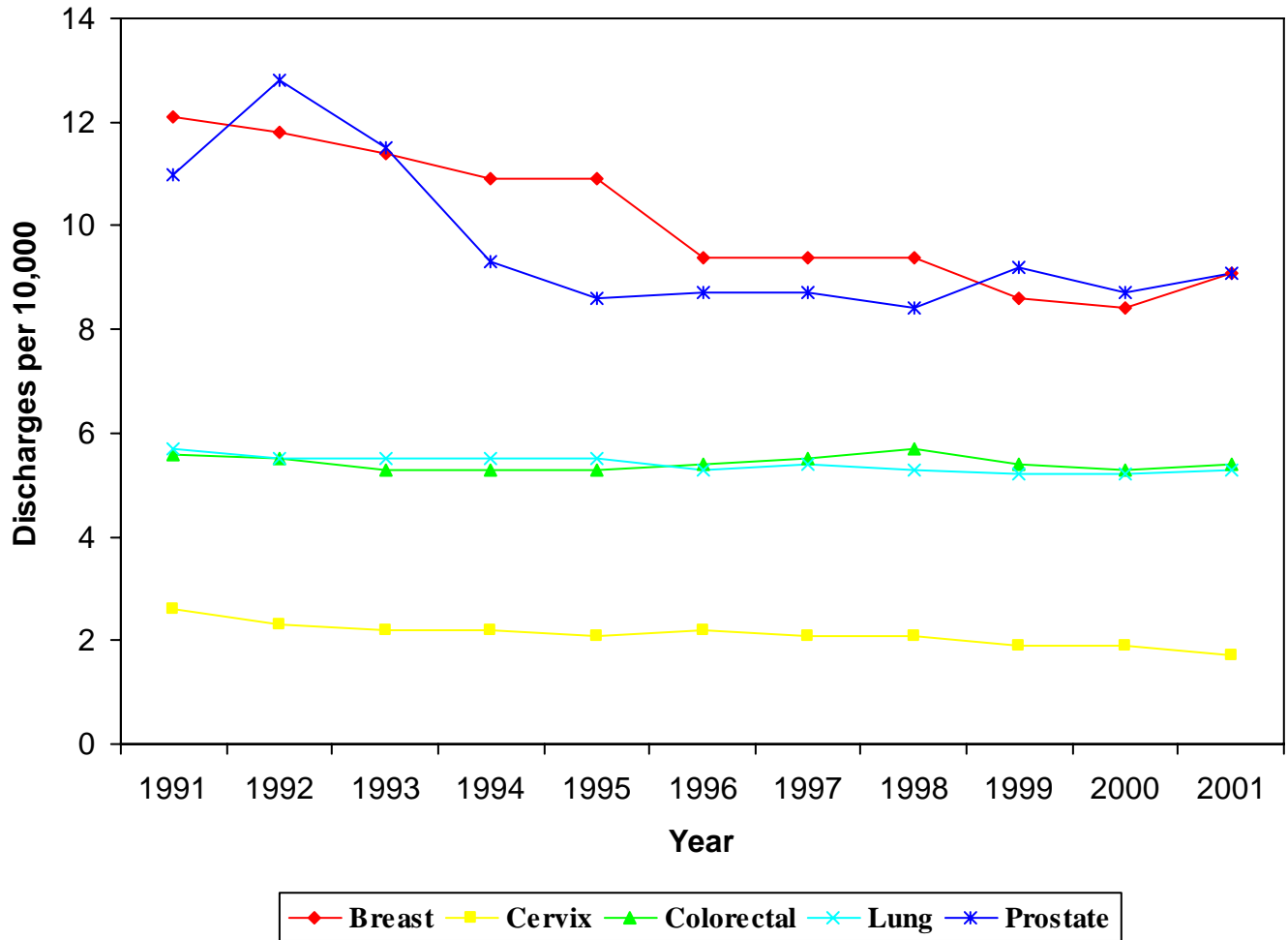
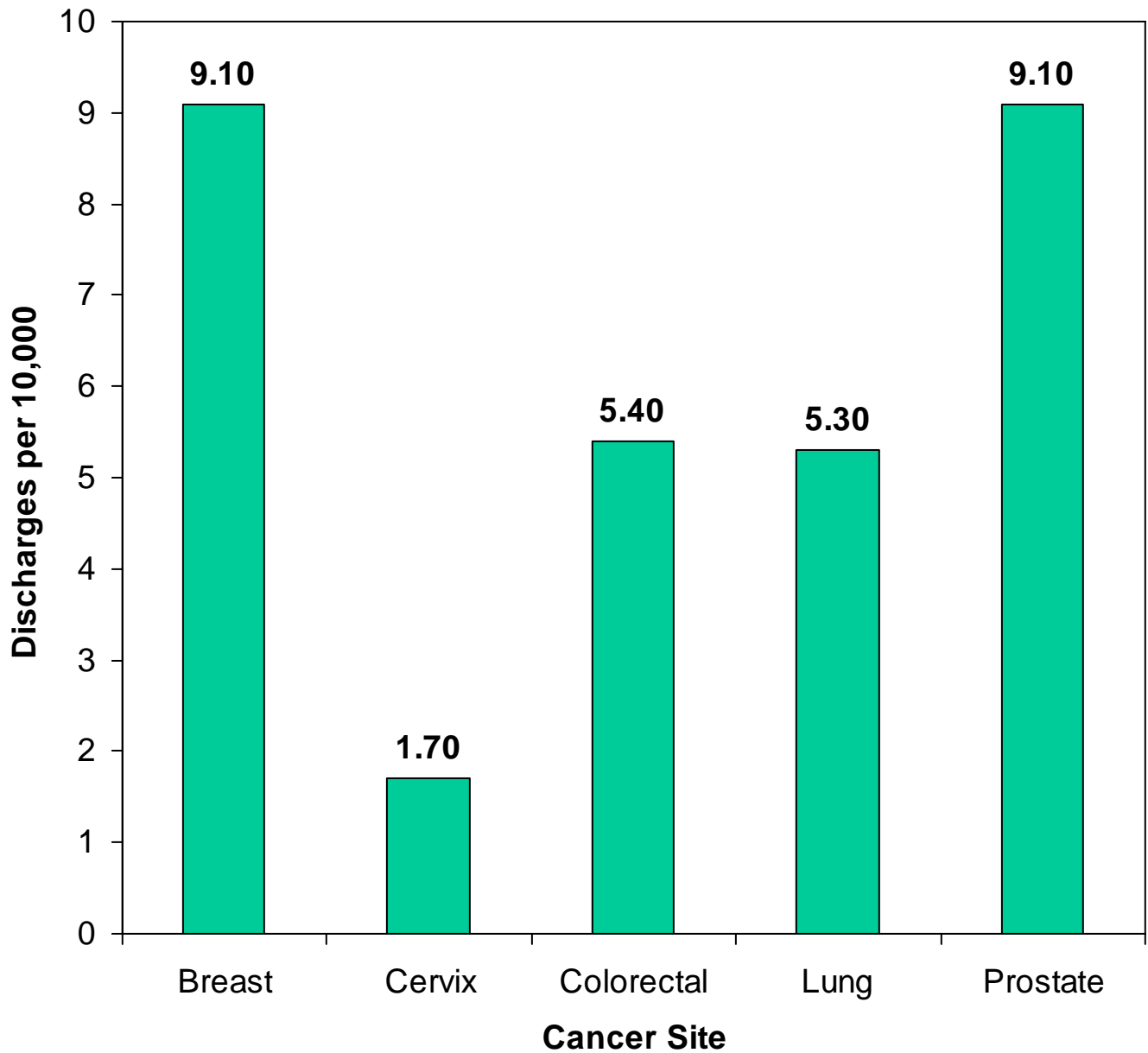


Chart 15.

Rates* of Hospital Discharge by Cancer Site, Michigan 2001



Appendix G: **Contact Information**

For more information about the Prostate Cancer Control Plan for Michigan or other cancer control activities in the state, contact Patricia Brookover, Comprehensive Cancer Control Program Director, at (517) 335-9620 or Sue Haviland, Manager of the Michigan Department of Community Health Cancer Prevention and Control Section, at (517) 335-8372.