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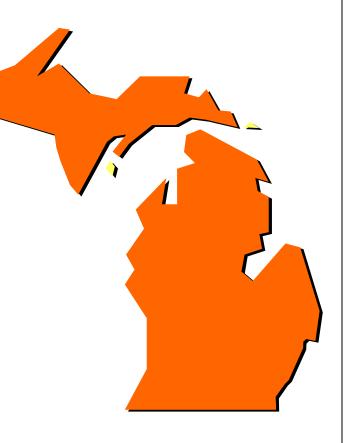
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Volume 9 (Issue 1)
Michigan Cancer Consortium Special Issue

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The mission of the Michigan Journal of Public Health is to promote public health practice, research, and policy with a primary focus on Michigan and the Great Lakes Region. We encourage contributions from the field of practice at the state and local level, global health, original research, opinion and commentary. It is the expressed interest of this Journal to encourage dissemination from the field of public health practice.

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EDITORIAL

Michigan Cancer Consortium Celebrates 20 Years

The Michigan Journal of Public Health (MJPH) invites you to celebrate 20 years of the Michigan Cancer Consortium (MCC) with this 2018 special issue.

Among the core principles and values of the Michigan Public Health Association are the beliefs that the effective principles and practice of public health professional disciplines are central to the health and well-being of Michigan's people and communities. MPHA believes that diversity within Michigan's populations, among various cultures, and between the professional health disciplines enhances and enriches the public's health. Lastly, we believe that inclusion of a variety of viewpoints, partnerships and teamwork involving broad representation of professionals and community members, and multidisciplinary interaction are essential to accomplishing significant improvements in the public's health.

In alignment with our core principles, the Michigan Public Health Association has dedicated this special issue to Michigan Cancer Consortium's accomplishments over the past twenty years.

The MCC is a statewide partnership of 100 organizations working to reduce Michigan's cancer burden. Its <u>mission</u> can best be defined by the words *collaboration* and *partnership*. This mission is important: *cancer is the second leading cause of death in Michigan; approximately 144 people are diagnosed with cancer and 56 people die from the disease each day in our state.*

At the time it was formally established in 1998, the MCC:

- Had 31 founding member organizations.
- Formed its first executive committee that year.
- Acted on priorities for cancer control in Michigan that were put into place.

Today, the MCC:

- Is nearly 100 members strong.
- Has a sustaining structure, including a <u>board of directors</u>, to facilitate collaboration and action around priority programs and other cancer prevention and control issues.
- Is accountable to an evidence-based cancer plan.
- Sponsors an <u>annual meeting</u> that regularly draws 200 attendees.
- Priorities for 2018-2019 include:
 - o **Prevention:** Increase HPV vaccination rates
 - o **Early Detection:** Increase the proportion of adults 50-75 years who are up-to-date on appropriate colorectal cancer screening
 - o **Diagnosis and Treatment:** Increase the percentage of Michigan adults participating in cancer clinical trials
 - o **Quality of Life:** Decrease the percent of Michigan adults diagnosed with cancer who report current physical pain due to cancer treatment.

MCC accomplishments and activities over the past 20 years include creating a dashboard as part of its website to track progress of MCC approved priorities, the MCC Annual Report, prostate cancer "Help After Treatment" guides for patients, tobacco dependence treatment partnership to help cancer patients, as well as receiving two national awards.

We thank the leadership of the MPHA for this special edition of the MJPH highlighting the work of MCC. We also thank the many MCC leaders and members who invested their expertise and time over the last 20 years. You have been difference makers. As past leaders and members have done, we also will continue to lay the groundwork for the MCC's future success. Here's to the next 20 years!

In health,

Lorena Disha, MPH President, MPHA Tom Rich, MPH MCC Co-Chair Dana Zakalik, MD MCC Co-Chair







National Editorial

The Comprehensive Cancer Control National Partnership Celebrates the 20th Anniversary of the National Comprehensive Cancer Control Program¹

This year marks the twentieth year that the Centers for Disease Control and Prevention (CDC) has supported the United States National Comprehensive Cancer Control Program (NCCCP). The NCCCP grew out of a movement called comprehensive cancer control (CCC), which began in 1994 and whose aim is to address cancer in a comprehensive manner, across the continuum of cancer control rather than focusing in on one cancer site (e.g. breast) or only on one aspect of care delivery (e.g. treatment). CCC is an approach that brings together multi-sector partners to collectively address the cancer burden in a community by leveraging existing resources and identifying and addressing cancer related issues and needs. The NCCCP began in 1998 with funding to six programs, including Michigan, to implement written cancer control plans through a statewide CCC coalition. In 1999, the Comprehensive Cancer Control National Partnership (CCCNP) was officially formed. This partnership brought together key federal and national cancer stakeholders to support both CCC programs and coalitions as they developed and implemented their CCC plans.

¹ Note: This editorial is written by the authors on behalf of the Comprehensive Cancer Control National Partnership

https://www.cccnationalpartners.org/. The authors would like to acknowledge the leadership and contributions of the CCCNP

Chair Cynthia Vinson, from the National Cancer Institute and Vice-Chair Frank Bright, from the National Association of Chronic Disease Directors.

In the first few years of the NCCCP, CDC and programs were working to define what CCC meant, how it could be useful in addressing the burden of cancer in a state, tribe or territory, and were often more focused on traditional public health issues like education about cancer prevention (tobacco, nutrition, physical activity, sun safety) and encouraging cancer screening. Since 1998, the NCCCP has grown from six to 66 funded programs. Now CCC programs and coalitions have taken a broader view of their role beyond prevention and early detection and have also focused on diagnosis, treatment and survivorship issues. The CCC approach has evolved within programs, coalitions and among national partners. Cancer plans and implementation of those plans now integrate advances in cancer control science and research, as well as place a focus on population based outcomes through policy, systems and environmental changes. CCC coalitions now routinely identify a set of priorities from cancer plans to focus on for implementation within a set period of time, increasing their ability to effectively leverage existing resources and focus on the "value-added" potential of the coalition – addressing issues that otherwise would not be addressed by one organization alone.

The CCCNP has grown along with the NCCCP and CCC coalitions. The CCCNP officially formed in 1999 and now includes 19 partners. The CCCNP supports CDC's priorities for the NCCCP, including: primary prevention and early detection of cancer; improving quality of life for cancer survivors through effective diagnosis, treatment and long-term support; focusing on policy changes for lasting change; promoting access to quality cancer-related care for all populations, and; evaluation of efforts and use of results for improvement.

CCCNP efforts are increasingly focused on encouraging coalitions to focus on addressing the cancer control issues where we have strong science and can achieve significant cancer outcomes for populations. These efforts include increasing human papillomavirus (HPV) vaccination

uptake, increasing colorectal cancer screening and addressing cancer-related disparities among populations, and improving the well-being of the growing population of cancer survivors in the US.

Since the CCC movement began in 1994, CCC coalitions have been considered "engines of change" that facilitate cancer control progress across the US. The CCCNP celebrates the achievements of the NCCCP and CCC coalitions over the past twenty years. The Michigan CCC Program and the Michigan Cancer Consortium exemplify the progress made through CCC. Together they, along with many collaborating partners, have made significant progress in addressing the burden of cancer in Michigan, from development of a statewide consensus agreement among cancer care providers, payers, advocates, and policy makers regarding cancer clinical trials; to establishment of the Dr. Ron Davis Smokefree Air Law; and, establishing a Survivorship Care Plan Learning Collaborative for cancer centers and health systems. Perhaps the greatest strength of the MCC and other CCC coalitions around the country is that they keep people as the center of their mission. While CCC is often considered to have three foundational pillars: programs, partnerships and plans, there is a fourth pillar – people. Whether it is those whose risk is reduced by receiving a HPV vaccination or a cancer survivor whose quality of life is improved through participating in a wellness program for cancer survivors, people remain the driving force for CCC coalitions.

As we think about the next ten to twenty years, we know that CCC programs and coalitions will remain important engines of change in the US. In 2018, CDC, the American Cancer Society and the National Cancer Institute have commissioned a study by the National Academies of Science, Engineering and Medicine to gather input that could lead to a national cancer control plan in the US. CCC coalitions are uniquely positioned to be the cornerstone of a US national cancer plan's

development and implementation. The CCCNP is working to ensure CCC coalitions are that cornerstone and will continue to work with CCC coalitions to address the most persistent cancer problems. Building on the success of the NCCCP and CCC coalitions across the country, we can conquer cancer together.

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Leslie Given, BA, MPA Strategic Health Concepts

Karin Hohman, RN, MBA Strategic Health Concepts

NOTES FROM THE FIELD

An Introduction to the Priorities of the Michigan Cancer Consortium

Polly Hager, MSN, RN

Michigan Department of Health and Human Services,

Cancer Prevention and Control Section

Cancer is the second leading cause of death in Michigan. Approximately 144 people are diagnosed with cancer and 56 people die from cancer each day in our state. For those under 80 years of age, cancer is the leading cause of death (Michigan Vital Records). Efforts to address cancer take place at many levels including federal, state, local, and organizational. Through this multi-level approach all areas and populations in Michigan are targeted with interventions intended to reduce the impact of cancer.

An important facet of this state's approach to cancer is the Michigan Cancer Consortium (MCC). The statewide coalition consists of nearly 100 diverse member organizations that address cancer using an evidence-based cancer plan. Michigan's plan reflects the cancer continuum and encompasses prevention, early detection, diagnosis and treatment, and quality of life. In order to focus its collective resources, the Consortium selected four priorities to address from 2016 through 2018.

The following four articles describe each priority of the MCC. The articles represent and are organized according to the cancer continuum, a) prevent cancer from occurring, b) promote early detection of cancer using tests that have been shown to reduce mortality, c) diagnose and treat patients using effective and appropriate methods, and d) optimize quality of life for people affected by cancer.

All articles address the efforts undertaken by workgroups assembled around each priority for 2016-2018 (implementation ended December 31, 2017). The work described in the articles was completed through collective effort. Each workgroup was led by one, or two, content experts and each workgroup received staff support. The contributions of content experts, staff, and workgroup members must be acknowledged and is critical to the successes and managing the challenges encountered.

It is helpful to know that workgroups were asked to undertake projects that addressed health equity and/or policy, system, and environmental change related to each priority. Health equity and policy, system, and environmental change are two of four pillars that support the cancer plan and its implementation. Work plans were developed to outline the projects and the MCC Board of Directors approved each one prior to implementation. Workgroups provided a mid-term status report to the Board in early 2017.

In the fall of 2017, the MCC Board of Directors selected four priorities for 2018 through 2020 (implementation will end December 31, 2019). Work has begun on the new priorities and those activities are mentioned in varying degrees within the articles. The leadership of the MCC, Board of Directors, MCC member organizations, and partners are vital to the successes you will read about.

This publication was supported by the Cooperative Agreement NU58DP006334 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

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- 1. 2015 Michigan Resident Death File, Michigan Department of Health and Human Services, Division for Vital Records and Health Statistics.
- **2.** Michigan Resident Cancer Incidence File. Includes cases diagnosed in 2014 and processed by the Michigan Department of Health and Human Services, Division for Vital Records and Health Statistics by November 30, 2016.

NOTES FROM THE FIELD

Working to Improve Human Papilloma Virus Vaccination Uptake in Michigan

Courtney Cole, Michigan Public Health Institute, Angela McFall, Michigan Department of Health and Human Services

The human papilloma virus (HPV) is a known carcinogen that causes most cervical cancers, as well as some cancers of the <u>vagina</u>, <u>vulva</u>, penis, anus, rectum, and <u>oropharynx</u> (Centers for <u>Disease Control and Prevention [CDC]</u>, <u>2018</u>). In Michigan, from 2010 – 2014, 1,314 people were diagnosed with HPV associated cancers (CDC, 2018). When identifying cancer prevention strategies to incorporate in the continuum of care, secondary prevention methods are the most common, and include cancer screenings, early detection, and progressive treatment. Vaccinations serve as a primary prevention method and the Food and Drug Administration (FDA) approved HPV Vaccine, reduces the incidence of cancer and the frequency of the virus. One of the Healthy People 2020 objectives is to achieve a HPV vaccine completion rate of 80% for males and females. Implementation of HPV evidence-based interventions and health education initiatives are imperative to achieve this goal.

In Michigan, HPV vaccine initiation and completion rates among adolescents aged 13-17 years old is less than 50% (MCIR, 2018). According to researchers, identified barriers associated with low HPV vaccine uptake include provider hesitancy, vaccine stigma, and low uptake amongst the male population (Southall, 2016). In the statewide *Cancer Plan for Michigan 2016-2020*, the reduction of cervical cancer through the increase in HPV vaccination is by 2020 to:

Increase the proportion of females and males ages 13-17 years who have received at least three doses of HPV vaccine from 24.2% (females) and 7.4% (males) to 80% (females and males).

The Michigan Cancer Consortium (MCC) Board of Directors selected this objective as one of four priorities for 2016-2017, thus the MCC HPV Vaccine Priority Workgroup was assembled. Upon examining the data, the priority workgroup members decided to focus the work plan on increasing HPV vaccinations in the Hispanic population in Michigan. The work plan for the HPV Vaccine Priority Workgroup included conducting focus groups with the Hispanic population to gauge HPV and cervical cancer specific knowledge and reactions to three advertisements about the HPV vaccine.

Focus group findings revealed women were the primary health care decision makers of the family and reported more sources of health information than their male counterparts. Sources of health information included physician contact, online health resources, friends, and family members. Specifically, women were interested in acquiring accurate information about the HPV vaccine related to dosing and age recommendations and were not aware that the vaccine could benefit boys as well as girls. The male focus group reported being unaware of the HPV and its effects on the male population. Both focus groups identified a need for Spanish language materials about HPV. Important aspects of communicating about HPV vaccination included addressing the parents, having a direct message, and making the information relatable to the Latino community.

The focus group outcomes resulted in translation of HPV public service announcements and an educational brochure into Spanish. A multi-media campaign using these materials was conducted. The campaign included radio ads on Spanish stations in Grand Rapids, Kalamazoo, and Big Rapids, as well as print ads in the Spanish language newspaper, Lazo Cultural. The MCC website includes the Spanish language resources developed during this project. In 2017, the HPV cancer plan objective was updated to incorporate new recommendations delineated by the CDC concerning dosing. In October of 2016 the CDC began recommending 2 doses of HPV vaccine for people starting the vaccination series before their 15th birthday rather than the previously recommended 3 dose series. Three doses are still recommended for people over the age of 15 or those with immunocompromising conditions to combat cancers associated with HPV infections (CDC, 2016). The updated project objective is by 2020 to:

Increase the proportion of females and males ages 13-17 years who have completed the recommended series of HPV vaccine to 80%.

With the 2016-2017 project complete, the HPV Vaccine Workgroup developed a project work plan for 2018-2019. This work plan utilizes the CDC's AFIX (Assessment, Feedback, Incentives, and eXchange) model to evaluate provider performance in offering and administering the HPV vaccine to clients 9-26 years old according to the current recommended vaccine schedule in five regions of the state. Efforts are already underway to implement the new work plan.

This publication was supported by the Cooperative Agreement NU58DP006334 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

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- 1. CDC. (2018, March). Cancers associated with human papillomavirus by state, 2010-2014. USCS data brief, no. 2. Atlanta, Georgia.
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NOTES FROM THE FIELD

Collaborative Efforts to Improve Cancer Survivor Quality of Life

Audra K. Putt, MPH, CPH, Michigan Department of Health and Human Services

An individual is considered a cancer survivor from the time of diagnosis through treatment and beyond. In Michigan, there are about 526,100 survivors (American Cancer Society, 2016). Survivors are living longer with the support from advancements in cancer care and treatment. However, they may still experience the effects of their cancer for years to come.

Survivorship Care Plans (SCPs) are one way to support survivors during the transition from oncology care to the primary care setting. The Commission on Cancer established Survivorship Care Plan Standard 3.3 in which cancer programs are to, "Develop and implement processes to monitor the formation and dissemination of a SCP for analytic cases with Stage I, II, or III cancers that are treated with curative intent for initial cancer occurrence and who have completed active therapy" (Commission on Cancer, 2016). The SCP provides a record of treatment, follow-up care recommendations, referrals to support services, and additional community resources (Commission on Cancer, 2016). SCPS support survivor quality of life by encouraging adherence to follow-up care and healthy lifestyle recommendations.

In 2016, the MCC Board of Directors selected SCPs as the 2016-2017 priority under the *Cancer Plan for Michigan's* Quality of Life Goal. The priority focuses on increasing the number of Michigan adults diagnosed with cancer who report receiving instructions on where to return or who to see for routine cancer check-ups after completing treatment. The MCC Survivorship Priority Workgroup, tasked with developing a project to support this effort, consists of professionals from different backgrounds with extensive knowledge on the needs of survivors.

The MCC Survivorship Priority Workgroup determined their project would involve creating five SCP resource documents for post-treatment survivors. These documents would accompany SCPs and provide education and resources on healthy behaviors that can improve quality of life during survivorship. Between July 2016 and August 2017, document topics were selected by the workgroup based on common survivorship questions or concerns and important public health interventions. These topics were physical activity, nutrition, tobacco cessation, fatigue, and healthy lifestyle choices. The documents are not intended to replace consultation with a health care provider; survivors should see their health care provider for regular medical care. The goal is for providers to share these documents with survivors who would benefit from learning more about the specific topic.

Since the cancer survivor population is diverse, it was determined the documents would be written with plain language and a reading level to accommodate survivors of various education levels. Plans were also set to translate the documents into two additional languages widely spoken in Michigan, Spanish and Arabic. The workgroup collaborated with partners in the Michigan Department of Health and Human Services, including the Tobacco Control Program, Division of Immunization, and Disability Health Unit, to review the documents that pertained to their content areas.

To test the resource documents for readability and usability, Institutional Review Board approval was received for a focus group with post-treatment cancer survivors. The focus group was organized in collaboration with St. Joseph Mercy Health System. Participants were asked to provide feedback on whether the five documents contained information beneficial to post-treatment survivors and were formatted in a manner they would find appealing and easy to read. It was concluded from focus group feedback that resource documents of this type should include:

- Additional resources related to the topic
- Citations for information provided
- Colorful pictures
- Plain language
- Bullet points

Focus group feedback was helpful to ensure the documents were meeting the needs of those individuals their use was intended for.

The five resource documents were approved by the MCC Board of Directors in November 2017 and made available for download on the MCC's website (see Appendix A for an example of the documents). The MCC Survivorship Priority Workgroup has promoted the documents at the MCC Annual Meeting and through various MCC communication channels. To evaluate use of the documents, metrics associated with document downloads from the MCC website will be monitored in 2018.

As the MCC Survivorship Priority Workgroup concludes their work on the SCP resource document project, they remain committed to improving the quality of life of Michigan cancer survivors. Over the next two years, the workgroup will focus on a new *Cancer Plan for Michigan* priority to reduce the percent of Michigan adults with cancer who report physical pain. Their project will involve creating a shared-decision making document for survivors that provides education on physical pain management. The workgroup and MCC are dedicated to meeting the unique needs of survivors as this population continues to grow.

This publication was supported by the Cooperative Agreement NU58DP006334 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

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Appendix A: Fatigue Resource Document

LIVING HEALTHY AS A CANCER SURVIVOR: FATIGUE

A cancer survivor is a person who has been diagnosed with cancer. They are considered a survivor for the rest of their life.

- There are both physical and emotional side effects of cancer and its treatment. These side
 effects will impact survivors in different ways.
- Choosing healthy behaviors is important. You can lower your risk of getting cancer again through exercise, eating healthy foods and not being overweight.
- This document provides survivors with information on ways to live healthy after treatment ends. The document should not replace consultation with a health care provider. It is important that all survivors see their health care provider for regular medical care.

Handling Fatigue as a Cancer Survivor

Fatigue is a common side effect of cancer treatment. Cancer related fatigue is not linked to recent activity. It does not always get better if you rest.

Physical fatigue- The body feels tired and a person may not feel they have energy to do activities.

Mental fatigue- A person has difficulty concentrating, solving problems, reading, and holding conversations. They may also experience anxiety and irritability.

Cancer treatment, pain, and other factors can cause fatigue. Talk to your health care provider about different ways to treat it.



Managing Your Fatigue

- 1. Be active. Being physically active can help you gain energy and lower stress.
 - American Cancer Society guidelines for physical activity include 150 minutes of moderateintensity exercise per week, like fast walking.
 - · Exercise using a DVD or YouTube video if it is hard to leave the house.
 - Consider yoga, biking, or other types of exercises.
 - Ask your health care provider and physical therapist about activities that are best for you.
 - Physical activity is the BEST way to decrease fatigue and increase energy.
 - · For some individuals, it may take time to overcome fatigue.

2. Eat healthy. Drink Lots of water.

- . Eat 2 cups of vegetables and 1 1/2 cups of fruit every day.
- . Try eating 5 or 6 small meals spaced out over the day, instead of 3 large meals.
- . If you drink coffee or tea with caffeine, only drink them in the morning.
- Drink at least 8 to 10 glasses (8 ounce) of water each day. Check with your health care
 provider if you have heart or kidney problems.

3. Create time during your day to rest.

- Go to bed at the same time every night, even on the weekends.
- Relax before going to bed by reading or listening to quiet music.
- · Get up at about the same time every morning.
- It is ok to take 1 or 2 short, 30-minute naps during the day. Try to be active after.

4. Distract yourself with fun activities.

- · Volunteer in your community.
- · Take time to visit with family and friends.
- · Read a book, meditate, listen to music or enjoy a hobby.

Helpful Resources for Survivors

- Call The American Cancer Society's National Cancer Information Center at 1-800-227-2345 for more information and resources.
- For more information on cancer related fatigue visit the <u>National Cancer Institute website</u>: https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq



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NOTES FROM THE FIELD

Increasing Colorectal Cancer (CRC) screening in Michigan

Sharde' Burton MPH, Michigan Department of Health & Human Services

Data collected by the Michigan Cancer Surveillance Program in 2014 shows that there were 4,608 cases of colorectal cancer diagnosed and there were 1,766 deaths from the disease. Regular screening is one of the best ways to prevent colorectal cancer. Screening can prevent colorectal cancer through the detection and removal of precancerous growths, as well as detect cancer at an earlier stage. The declines in colorectal cancer incidence in recent years (about 3% per year from 2004-2013) have mainly been attributed to early detection (American Cancer Society, 2017).

Michigan has been working to address colorectal cancer screening for over 20 years. Recent efforts include:

- Attending the first national 80% by 2018: Colorectal Cancer Forum in September 2015.
- Developing an action plan while at the Forum to address the 80% by 2018 pledge.
- Michigan and its Michigan Cancer Consortium (MCC) took the pledge to work towards a goal of screening 80% of Michigan residents for CRC by 2018.

The Michigan Cancer Consortium's (MCC) Colorectal Cancer Priority Workgroup implemented a statewide project from 2016-2017 with a goal to initiate colorectal cancer (CRC) screening as a quality measure for Michigan Medicaid. CRC screening is currently a HEDIS measure for commercial insurance plans and Medicare. Quality measures are tools that help measure or quantify healthcare processes, outcomes, patient perceptions and organizational structure and/or systems that are associated with the ability to provide high-quality health care and/or that relate to one or more quality goals for health care. These goals include: effective, safe, efficient, patient-centered, equitable and timely care. The Centers for Medicare & Medicaid Services (CMS) uses quality measures in its quality improvement, public reporting, and pay-for-reporting programs for specific healthcare providers.

States with colorectal cancer screening as a Medicaid quality measure, such as New York, show increased screening rates for their members. According to the 2013 National Health Interview Survey data, only 36% of Medicaid-insured adults nationwide were up to date with US Preventative Services Task Force colorectal cancer screening recommendations compared to at least 60% of privately or Medicare insured adults (Fedewa et al., 2015), while the state of New York had a screening rate of 59% for Medicaid insured adults in 2014 (NY State Dept. of Health, 2015).

The MCC Colorectal Cancer Priority Workgroup identified partners in their goal to initiate CRC screening as a quality measure as: key leaders with Michigan Medicaid, staff of the National Colorectal Cancer Round Table, leaders with the American Cancer Society Cancer Action Network and American Cancer Society, Inc., Lakeshore Division. The workgroup drafted a letter to key leaders at Michigan Medicaid and a meeting with those leaders followed. The letter gave background information and recent data from studies on colorectal cancer. The idea that CRC screening should be a quality measure was well received, but it was recommended

to be presented at a later date, as the state's amended plan was in the process of being approved by CMS. The state's amended plan would include CRC screening as a preventive benefit for state Medicaid members. Upon approval of the state's amended plan within a year after the initial meeting, the MCC Colorectal Cancer Priority Workgroup followed up with key leaders of Michigan Medicaid. While CRC screening has not yet been made a quality measure of Medicaid in Michigan, many efforts are currently in place to make it so and meetings with the partners described above continue.

Moving forward, the Colorectal Cancer Priority Workgroup will continue its efforts to improve colorectal cancer screening rates in Michigan. The workgroup will focus on proven intervention strategies to increase colorectal cancer screening rates. Following are the evidence-based interventions (EBI's) the workgroup will focus on to increase screening rates:

- Client reminders
- Provider reminders
- Reducing structural barriers
- Provider assessment and feedback

The workgroup will promote these evidence-based interventions among the Michigan Cancer Consortium member organizations through a policy, systems, and environmental (PSE) change project. The combination of continued work to initiate CRC screening as a quality measure and implementation of a PSE change project are important efforts to increase the colorectal cancer screening rates in Michigan.

This publication was supported by the Cooperative Agreement NU58DP006334 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

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NOTES FROM THE FIELD

Expressway to Cancer Clinical Trials: Reducing Administrative Barriers to Enrollment

Audra Putt, MPH, CPH, Michigan Department of Health and Human Services

For nearly 20 years, the Michigan Cancer Consortium (MCC) has been involved in efforts with a variety of stakeholders to increase cancer patient participation in clinical trials. In 2001, the MCC partnered with the Michigan Working Group to Improve Cancer Outcomes on the development of the *Consensus Guidelines for Healthcare Coverage of Routine Patient Care Cost Associated with Oncology Clinical Trials*. The goal of this Consensus Agreement's creation was to increase participation in specific cancer-related clinical trials by supporting the predictability of payment for clinical trial services. The voluntary Consensus Agreement includes a framework detailing third party payer coverage of patient costs in relation to their benefit plan for clinical trial enrollment. Members of the Michigan Association of Health Plans supported the Consensus Agreement and agreed to increase participation in cancer-related clinical trials through coverage of routine costs associated with participation. A 2015 assessment supported by the MCC found clinical trial coverage through larger Michigan health plans (including Medicaid and Medicare) generally aligns with the Consensus Agreement.

With changes related to health care coverage through the Affordable Care Act and advancements in treatment, the MCC Board of Directors selected increasing cancer clinical trial enrollment as the 2016-2017 priority under the *Cancer Plan for Michigan*'s Diagnosis and Treatment Goal in 2016. The MCC Clinical Trials Priority Workgroup was tasked with developing a project to support this effort. The workgroup convened with the goal to ensure Michigan residents with cancer who want to join a clinical trial can do so with fewer barriers. In 2016, 7 percent of Michigan adults who reported a cancer diagnosis also reported participating in cancer treatment clinical trials (Michigan Department of Health and Human Services, 2016).

The workgroup began by surveying stakeholders with the MCC and Michigan Society of Hematology and Oncology (MSHO) to assess barriers to clinical trial enrollment. Survey results indicated that providers had concerns with the sometimes-lengthy clinical trial enrollment process. As a result, the workgroup decided their project would address prior authorization concerns. Insurers often require prior authorization for cancer clinical trial enrollment, and ask for different pieces of information. This can lead to communication barriers between providers and insurers. In some instances, patient enrollment can be delayed by weeks while prior authorization is approved. The workgroup project focused on facilitating more rapid response to prior authorization requests by creating a fax cover sheet that could be shared with practitioners and used as a "heads up" when enrolling patients in cancer clinical trials.

The fax cover sheet was created for use when a health insurance carrier requires prior authorization for participation in a cancer clinical trial. It asks for such information as why the patient is eligible to participate, the therapeutic purpose for conducting the trial, and whether the trial is federally funded (see Appendix A for the fax cover sheet). Use of the fax cover sheet intends to simplify the prior authorization process and reduce the time needed to prepare and receive approval for authorization, thus decreasing the administrative burden for providers and insurers. The MCC Board of Directors approved the fax cover sheet in August 2016 and made it available as a fillable form on the MCC Website.

After development of the fax cover sheet, the workgroup established a promotion plan for sharing it with various stakeholders and partners. Steps were taken to promote the fax cover sheet at the MCC Annual Meeting, on the MCC Website, at hospital cancer committee meetings, and with partner newsletters. Following promotion, an evaluation plan for determining the cover sheet's reach was also established. In 2017, it was downloaded from the MCC website 261 times. Questions about knowledge and use of the fax cover sheet were included in the 2017 MCC Annual Survey. MSHO members were also surveyed on similar questions in the fall of 2017. The results from both surveys (Figure 1) indicated there is still work to be done with promoting the fax cover sheet.

	Michigan Cancer Consortium Member Survey	Michigan Society of Hematology and Oncology Member Survey
Number of respondents (N=)	86	111
Aware of the cover sheet	23 (26.7%)	21 (18.9%)
Used the cover sheet in their office	3 (3.5%)	12 (10.9%)

Figure 1. Partner Knowledge and Use of the Clinical Trials Fax Cover Sheet Form

Over the next two years, the workgroup will continue to promote cancer clinical trial enrollment. A new project will be undertaken by the workgroup to develop infographics for patients and primary care providers, detailing the benefits of clinical trial enrollment. To support health equity, the infographics will meet accessibility guidelines. The MCC and Clinical Trials Priority Workgroup will remain dedicated to providing support and resources to increase the number of Michigan adults with cancer who participate in cancer clinical trials.

This publication was supported by the Cooperative Agreement NU58DP006334 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

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Appendix A: MCC Clinical Trials Cover Sheet



The Michigan Cancer Consortium strongly supports facilitation of patient participation in cancer clinical trials.

This cover sheet was created for use when prior authorization for participation in a cancer clinical trial is required by a health insurance carrier

Member	
Date:	
Last name:	First name:
ID #:	DOB:
Provider:	Facility:
Provider tax ID:	Facility tax ID:
Address:	Address:
Provider phone: Fax:	Facility phone:Fax:
Contact name:	Contact name:
Diagnosis:	Diagnosis code(s):
Brief description of trial (may attach copy of trial proto	
disabling disease that is causing serious clini	ned as: terminal illness, or a chronic, life-threatening, severely ical deterioration.
	disease prevention 🗌 disease detection or diagnosis 🗌 disease
treatment 3. Clinical trial is a Phase I, Phase II, Phase III, Phase III	
treatment 3. Clinical trial is a Phase I, Phase II, Phase II. 4. Trial meets at least one of the following requirem A. Federally funded trials approved or funde The National Institutes of Health The Centers for Disease Control and The Agency for Healthcare Research The Center for Medicare and Medica Cooperative group or center of any of the Department of Veterans Affar Qualified non-governmental research of Health for center-support gran The Department of Veterans Affairs; conditions described in the medi B. The study or investigation is conducted using the support of the study or investigation is conducted using the support of the study or investigation is conducted using the support of the study or investigation is conducted using the support of	e III, or Phase IV clinical trial sents (A, B, C, or D): ed by <u>one or more</u> of the following (check all that apply): If Prevention In and Quality Id Services If the four entities listed above or the Department of Defense or irs In entity identified in the guidelines issued by the National Institutes its The Department of Defense; The Department of Energy when cal policy are met. Inder an investigational new drug application reviewed by the Food
treatment 3. Clinical trial is a Phase I, Phase II, Phase II, Phase II. 4. Trial meets at least one of the following requirem The National Institutes of Health The Centers for Disease Control and The Agency for Healthcare Research The Center for Medicare and Medica Cooperative group or center of any of the Department of Veterans Affa Qualified non-governmental research of Health for center-support gran The Department of Veterans Affairs; conditions described in the medi B. The study or investigation is conducted u and Drug Administration. Include IND number her	e III, or Phase IV clinical trial sents (A, B, C, or D): ed by <u>one or more</u> of the following (check all that apply): If Prevention in and Quality sid Services of the four entities listed above or the Department of Defense or irs in entity identified in the guidelines issued by the National Institutes sits The Department of Defense; The Department of Energy when cal policy are met.
treatment 3. Clinical trial is a Phase I, Phase II, Phase II. 4. Trial meets at least one of the following requirem A. Federally funded trials approved or funder the National Institutes of Health The Centers for Disease Control and The Agency for Healthcare Research The Center for Medicare and Medicate Cooperative group or center of any of the Department of Veterans Affairs; conditions described in the medical B. The study or investigation is conducted upon Drug Administration. Include IND number here.	e III, or Phase IV clinical trial sents (A, B, C, or D): ed by one or more of the following (check all that apply): If Prevention and Quality sid Services of the four entities listed above or the Department of Defense or irs an entity identified in the guidelines issued by the National Institutes sits The Department of Defense; The Department of Energy when cal policy are met. under an investigational new drug application reviewed by the Food re:
treatment 3. Clinical trial is a Phase I, Phase II, Phase II. 4. Trial meets at least one of the following requirem The National Institutes of Health The Centers for Disease Control and The Agency for Healthcare Research The Center for Medicare and Medica Cooperative group or center of any of the Department of Veterans Affa Qualified non-governmental research of Health for center-support gran The Department of Veterans Affairs; conditions described in the medi B. The study or investigation is conducted u and Drug Administration. Include IND number her application. Name of trial sponsor here: D. The study is a clinical evaluation of a leg (IDE) from the	e III, or Phase IV clinical trial sents (A, B, C, or D): ed by one or more of the following (check all that apply): If Prevention and Quality sid Services of the four entities listed above or the Department of Defense or irs an entity identified in the guidelines issued by the National Institutes sits The Department of Defense; The Department of Energy when cal policy are met. under an investigational new drug application reviewed by the Food re:

RESEARCH & PRACTICE

Lessons Learned from Revising the Cancer Plan for Michigan

OVERVIEW

The burden of cancer in Michigan is large and eliminating the burden requires a comprehensive approach. Cancer is the second leading cause of death in Michigan and is the leading cause of death for people under 80 years of age (Michigan Department of Health and Human Services, 2018). The American Cancer Society estimates there will be 56,590 new cases of cancer in Michigan and that 21,380 Michiganders will die from cancer during 2018 (Cancer Facts and Figures 2018, 2018). Michigan is the 10th most populous state in the country (U.S. Census Bureau, 2014) and has the 7th greatest number of cancer survivors, estimated at approximately 526,100 in 2016 (American Cancer Society, 2016).

Comprehensive cancer control (CCC) is a collaborative way to address cancer through partnerships and sharing resources. The Centers for Disease Control and Prevention (CDC) funds state, territories, and tribal CCC programs to develop, implement, and maintain cancer plans to guide CCC work (National Comprehensive Cancer Control Program (NCCCP), 2017). Cancer plans "identify how an organization addresses cancer burden as a significant public health challenge. They are data-driven, evidence-based blueprints for action" (Centers for Disease Control and Prevention, 2018). The Comprehensive Cancer Control Implementation Building Blocks suggest that when CCC priorities are implemented it will lead to both short and long-term outcomes, one of which is decreased morbidity and mortality (Rochester, Townsend, Given, Krebill, & Balderrama, 2010). CDC directs each CCC program to work with its partners to develop their plan (Cancer Plan Self-Assessment Tool, 2013).

The most recent version of the Cancer Plan for Michigan was in place from 2009-2015 and was updated periodically. But, given the rapidly advancing science of cancer care and population health interventions, by 2015 the plan no longer fully reflected state-of-the-art cancer research and innovations. In order for Michigan's Cancer Plan to direct CCC priorities and activities in the state, revisions were needed. To address this problem, Michigan developed and completed a process to update its Cancer Plan. The CCC program used its long-term experience, expertise, and network of partners to guide the necessary revision of the Cancer Plan (Hager, Given, Redmond, & Rogers, 2010) (Miller, Hager, Lopez, Salinas, & Shepherd, 2009). The objectives of this article are to describe the revision and implementation of the Cancer Plan for Michigan, to outline community engagement efforts and stakeholder involvement in the process, and to present outcomes of the cancer plan revision process.

DESCRIPTION

Michigan's CCC Program is coordinated and staffed by the Michigan Department of Health and Human Services (MDHHS), which also supports its partner, the Michigan Cancer Consortium (MCC). The MCC is a network of approximately 100 dedicated public, private, and voluntary organizations that implement cancer plan activities. The coalition includes members that represent the following organizational categories: health systems, insurance plans, local health departments, research institutions, universities, trade organizations and special population groups. While these organizations may have varied interests, working together through the MCC they

share resources and knowledge, reduce duplicative efforts, maximize resource use and develop strategic attacks against the cancer burden in Michigan.

With a diverse representation of member organizations, the MCC collectively serves a wide array of populations throughout the state of Michigan. In the 2017 MCC Annual Survey, 77% of member organizations (n = 86) reported serving people with lower socioeconomic status, 72% reported serving the black or African American population, 62% reported serving people of Hispanic/Latino ethnicity, 58% reported serving people with a disability, 57% reported serving an Asian and Arab/Middle Eastern population, and 55% reported serving the Native American population. MCC members also reported that they serve the lesbian, gay, bisexual, and transgender community and refugees. Michigan has a mix of urban, suburban, and rural communities. Approximately 74% of MCC members serve both rural and urban areas, 7% serve rural areas exclusively, and 11% serve urban communities exclusively.

The diversity of MCC organizations and the expertise of its members offers unique opportunities for Michigan's Cancer Plan implementation. Coalitions have an understanding and belief that the cancer burden will decline through successful coordinated action (Rochester, Townsend, Given, Krebill, & Balderrama, 2010). Michigan has made significant progress toward the achievement of many goals and objectives since beginning its CCC work with the CDC (True, Kean, Nolan, Haviland, & Hohman, 2005). Table 1 shows examples of the evolution of the Cancer Plan objectives over the lifetime of the MCC. The MCC member organizations engaged in and reported on multiple cancer control activities and these efforts were monitored and evaluated to determine progress and impact. Still, given advances in the field of cancer control a fully revised cancer plan was needed to direct the state's cancer control activities for the next five years.

Table 1. The evolution of objectives over the history of Michigan's Caner Plans.

	1998-2002	2009-2015	2016-2020
Colorectal Cancer Screening	By 2004, increase to 50 percent the proportion of average-risk people with a life expectancy of at least five years who have received appropriate colorectal cancer screening. (Baseline: 17.3 percent of people in 1992)	By 2015, increase to 75 percent the proportion of averagerisk people in Michigan who report having received appropriate colorectal cancer screening and follow-up of abnormal screening results.	Increase the proportion of adults aged 50 to 75 years who are up-to date on appropriate colorectal cancer screening from 71% to 80%.19
End-of- life Care	By 2005, increase the timeliness of referrals to end-of-life services for breast, cervical, colorectal, lung, and prostate cancer patients.	By 2015, increase cancer patients' and caregivers' understanding of options for: 1) care up to, and during, the last phase of life, and 2) pain and symptom relief.	of Michigan adult cancer patients who are enrolled in hospice within 3 days of their death from 14.3% to

Michigan's objective of revising the cancer plan was to create an updated blueprint to guide CCC work in the state. Building on the strong foundation in place for comprehensive cancer control in Michigan, two key outcomes of interest were identified for the strategy to revise the Cancer Plan for 2016-2020: 1) create a plan that meets criteria outlined by the MCC Evaluation Committee and 2) revise the plan using an efficient strategy that offers multiple venues for stakeholder participation.

In the fall of 2014, one year prior to when the 2009-2015 Cancer Plan came to a close, the MCC convened its Evaluation Committee, a group of stakeholders with expertise in evaluation, to guide and facilitate the revision process. The MCC Evaluation Committee, with support from expert consultants, developed the plan structure, revision process and timeline, and presented them to the MCC Board of Directors for approval. The evaluation committee represented the planning level of stakeholder input while the MCC Board of Directors represented the decision-making level of stakeholder input.

The first step to determine desirable parameters for the Michigan Plan was to look at cancer plans from other CCC programs, including Minnesota and New York. The Evaluation Committee recommended the following for Michigan's Cancer Plan content, layout, and features:

- 1. Reduce the overall length of the Cancer Plan to less than 50 pages.
- 2. Align the overarching goals with the continuum of cancer care.
- 3. Limit the number of objectives and strategies under each goal area.
- 4. Use common criteria to select the objectives and strategies while ensuring they are data driven and evidence based.

In January and February 2015, CCC staff reviewed the existing Cancer Plan to assess how it compared with recommendations set forth by the Evaluation Committee. The assessment revealed that the Cancer Plan was 100 pages above the recommended length, had 14 goals, none of which were aligned with the continuum of cancer care, and none of the objectives were specific, measurable, achievable, relevant, and timely (SMART).

During the same time period, the Evaluation Committee narrowed down the goals for the Cancer Plan to four modeled after the national CCC program priorities (Centers for Disease Control and Prevention, 2017):

- 1. Prevent cancer from occurring.
- 2. Promote early detection of cancer using tests that have been shown to reduce mortality.
- 3. Diagnose and treat all patients using the most effective and appropriate methods.
- 4. Optimize quality of life for every person affected by cancer.

The Evaluation Committee considered including health equity; policy, systems, and environmental changes; active partnerships; and continuous evaluation as goals. However, since these principles can be applied across the full continuum of cancer care, the Committee established them as "pillars"-- overarching concepts that should be incorporated into implementation of the Cancer Plan. Once the goals and pillars were defined, the Committee developed a systematic process that included ways to engage MCC members in the revision.

After the Board of Directors approved the process in March 2015, the MCC created four workgroups, one to address each goal for the revised Cancer Plan. Workgroups consisted of two co-chairpersons, one MDHHS staff person and one subject matter expert from the MCC. Individual MCC members volunteered to participate in the workgroups. The number of members in each workgroup ranged from 12 to 21. The co-chairs for each workgroup held a planning session by phone prior to the first meeting of their group.

In order to develop plan objectives, MDHHS staff compiled a list of topics each goal might include. For example, the goal related to prevention of cancer included topics such as healthy eating, physical activity, HPV vaccination, tobacco use, and alcohol use. MDHHS staff developed worksheets with a list of potential SMART objectives for each topic. Every objective was linked to a consistent data source and included baseline data, if available.

Workgroups were given instructions (Figure 1) which outlined the revision process. In April 2015 the workgroups met over teleconference and used a worksheet (Figure 2) to narrow down the list of objectives using common criteria and to determine a realistic target to achieve for each objective by 2020.

Figure 1. Guidance for updating the Michigan Cancer Plan. This figure illustrates the guidance document outlining the revision process of the Cancer Plan for Michigan.

Figure 1. Guidance for updating the Michigan Cancer Plan. This figure illustrates the guidance document outlining the revision process of the Cancer Plan for Michigan.



Guidance for Updating the Michigan Cancer Plan

Thank you for participating in the process of updating the MI cancer plan. The MCC Evaluation Committee has defined the plan update process and reviewed other state cancer plans to identify desired content, layout and features to incorporate into the MI cancer plan. The MCC Evaluation Committee recommended and the MCC Board of Directors approved the following decisions related to updating the MI cancer plan:

- . Reduce the overall length of the cancer plan, making it no more than 50 pages
- Reduce the number of goals in the plan there should only be one overarching goal per section of the plan, using the continuum of cancer care, e.g. prevention, early detection, etc. The MCC Evaluation Committee has finalized a set of goals for the plan.
- Reduce the number of objectives in the plan the recommendation is to include no more than 10 objectives
 per goal, if feasible.
- Use common criteria for choosing objectives and strategies to include in the cancer plan these will be listed on
 worksheets that will guide the update process.

We are now ready to take the next steps in the plan update process, including:

- → Reviewing current and suggested cancer plan objectives
- → Reviewing current and suggested evidence-based strategies for each objective

Overall Timeline

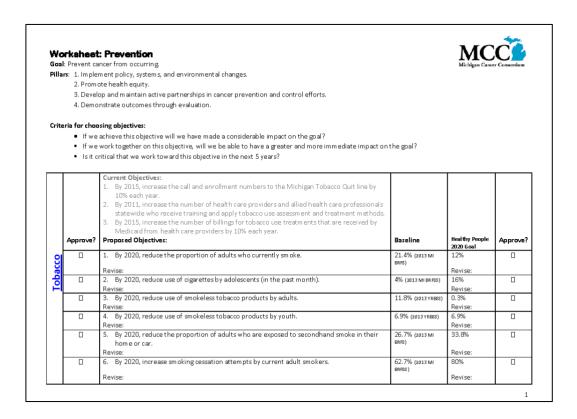
- March 2015 Form MCC Plan Update Workgroups and orient Workgroup Chairs
- April 2015 Finalize draft plan objectives
- May 2015 Finalize draft plan strategies
- By June 15 MCC Evaluation Committee review of full set of draft plan objectives and strategies
- · At June 25 MCC Board of Directors Meeting Recommend approval of draft plan objectives and strategies

Next Steps in the Update Process

Cancer Plan Update Workgroups will utilize the following steps in reviewing their section of the cancer plan objectives and strategies:

- 1. Plan Update Workgroup Conference Call #1:
 - a. Review the current and suggested cancer plan objectives, with baselines and targets. Note: Links to additional data are included in the worksheet for your section of the plan.
 - Discuss and decide if the suggested objectives should be revised. If no, mark "approved". If yes, mark
 "revise" and record the revised objective statement and/or target in the space provided on the
 - c. After the call the Workgroup chair will work with the staff person assigned to the Workgroup to finalize the list of objectives for your section of the plan. The final list of objectives is due by the end of April 2015.
- 2. Plan Update Workgroup Conference Call #2:
 - a. Review the current and suggested cancer plan strategies for each objective your group approved
 - b. Discuss and decide if the suggested strategies should be revised and/or if additional strategies are needed. If no, mark "approved". If yes, mark "revise" and record the revised strategy statement(s) in the space provided on the worksheet.
 - c. After the call the Workgroup chair will work with the staff person assigned to the Workgroup to finalize the list of strategies for your section of the plan. The final list of strategies is due by the end of May 2015.

Figure 2. Worksheet for selecting objectives. This figure illustrates the worksheet used by Cancer Plan workgroups to select the objectives that would be included in the Cancer Plan for Michigan.



Once the workgroups had a final list of objectives, MDHHS staff researched evidence-based strategies for each objective. In May 2015, a second teleconference meeting was held with each workgroup to choose the final list of strategies for each objective. A worksheet with criteria for choosing strategies was used to narrow down the list. At the end of the revision process, there were 36 objectives and 111 strategies across the 4 goals. The final objectives and strategies were vetted by the Evaluation Committee and then approved by the Board of Directors in June 2015.

Although the plan covers the full cancer continuum, it was recognized that the MCC is not able to actively work on all 36 objectives. In order to be more strategic in implementing the plan, the MCC involved its partners in a process to select priorities. It was a deliberate decision to prioritize one objective in each goal area so the full cancer continuum is represented. Many stakeholders were involved in the prioritization process. Workgroup members completed an online survey to vote on the top two priority objectives within their goal. The objectives that received more than 50% of the votes were reviewed by the Evaluation Committee and presented to the Board of Directors in September 2015. The Board of Directors, the Evaluation Committee, and workgroup co-chairs discussed the feasibility and impact of achieving those objectives, and then the Board of Directors voted to determine the final four priority objectives. The MCC focused its efforts on the priority objectives during the first two years of the Cancer Plan, 2016 through 2017.

DISCUSSION AND EVALUATION

The first goal of Michigan's cancer plan revision process was to create a plan that meets the criteria outlined by the MCC Evaluation Committee. This goal was achieved, as evidenced by the Cancer Plan available on the MCC's website, www.michigancancer.org (Michigan Cancer Consortium, 2017). Michigan's Cancer Plan for 2016-2020 is a 27-page document, well below the 50-page recommendation, that includes 36 SMART objectives across the four goal areas and each objective has a list of suggested evidence-based strategies. As previously described, the cancer plan goal areas are aligned with the cancer continuum. Worksheets and specific selection criteria were used to guide selection of objective and strategies. This planning and structure worked well to shape workgroup conversations and efficiently use workgroup members' time. The structure allowed workgroup members to suggest cancer plan topics not included in the prepared worksheets and the pre-established selection criteria kept those workgroup discussions focused.

However, this structure presented a few key challenges. The planning and worksheet preparation was time intensive for the MDHHS staff supporting the cancer plan revision process. Also, it was difficult to apply the same standards across the cancer continuum. Some areas had a wealth of established resources, such as The Guide to Community Preventive Services (The Community Guide) (Community Preventive Services Task Force, n.d.), while in other areas the science was just emerging so the level of evidence and ease of locating evidence was different. For example, there were extensive data and a large selection of Healthy People 2020 (U.S. Department of Health and Human Services, 2018) objectives and Community Guide strategies available for reference for most suggested topics in the prevention and early detection goal areas. The largest task for the prevention and early detection workgroups was to narrow the focus and select the most important objectives and strategies to improve the health of Michiganders. The diagnosis and treatment and quality of life workgroups had the opposite problem. Healthy People 2020 and the Community Guide offered minimal suggestions for objectives and strategies in these areas. In addition, there were limited statewide data in these areas, which restricted possibilities for SMART objectives.

Creating a cancer plan with SMART objectives highlighted that most public health data sources have limits in their ability to depict the needs of certain Michigan populations. Health equity was one of the pillars that all workgroups were asked to incorporate into the objectives. However, most statewide data was not consistently available for sub-populations, which limited the ability to demonstrate health disparities. In an effort to tackle this issue, after the completion of the Cancer Plan, Michigan began a process to identify additional data sources to better measure public health interventions across the cancer continuum for all Michigan populations.

The second goal was to use an efficient revision strategy that offered multiple venues for coalition stakeholder participation. The MCC requested volunteers to shape the Cancer Plan for Michigan around the four cancer continuum goal areas. This solicitation for volunteers differed from past processes because experts on a wide variety of topics were solicited at once. Still, a sufficient number of members were recruited for the workgroups. Some workgroup volunteers were active in the MCC and some had not been actively engaged prior to this cancer plan revision process. The revision process provided all MCC members an opportunity to offer their expertise along the full cancer continuum. Workgroup members were able to provide input on Cancer Plan objectives and strategies during multiple conference calls that were scheduled based on member availability. Workgroup members were also able to provide feedback by email throughout the process.

Thanks to a straightforward process and great stakeholder participation, Michigan now has a measurable cancer plan and a clear strategy for monitoring progress towards achieving the plan objectives (Michigan Cancer Consortium, 2017). Having such a structured, concise cancer plan and timing its release with the MCC Annual Meeting in November 2015 helped engage leaders, including national leaders, state government administration, and state health department leadership, in the release of the Cancer Plan while also bringing it to their attention. Moving forward, Michigan is adapting and applying the process used to revise the cancer plan, including the commitment to methodical preparation, to the MCC's Cancer Plan implementation activities.

The structured process that Michigan used to revise the state Cancer Plan resulted in a data driven plan created with involvement from a large number of stakeholders from across the state and across sectors. The process involved the development of guidance documents with criteria for the stakeholder workgroups to use when making decisions. It also involved worksheets to lay out potential cancer plan objectives and strategies and help workgroup members use the decision criteria to select objectives and strategies. This helped structure workgroup meetings and email communications and facilitated an efficient and transparent decision making process.

NEXT STEPS

There are a few things that will be done the next time the cancer plan is revised. First, provide clear written guidance on what it will mean to incorporate the cancer plan pillars of policy, systems, and environmental change, health equity, active partnerships, and evaluation, into the cancer plan objectives and strategies. While the pillars were stated and considered in the process of creating the 2016-2020 plan, there was no clear guidance on how to incorporate them into the plan.

Second, put in place a formal process to gather input from statewide chronic disease program partners. Given existing collaborative relationships, a few staff from other chronic disease programs in Michigan participated in the cancer plan workgroups but there is opportunity for more engagement in the future.

Third, have an evaluation plan to determine stakeholder satisfaction with the process. While MDHHS staff have received informal positive feedback, there was no official evaluation system in place.

The structured process and supporting guidance document and worksheets that Michigan used facilitated effective engagement of a broad base of stakeholders and resulted in a Cancer Plan that met the pre-established criteria. The staff anticipate that with some adaptations the process will continue to work well in the future. The authors encourage other CCC programs that use other stakeholder engagement and cancer plan revision processes to share their experiences.

KEY FINDINGS

- A structured process helped involve a wide array of public and private stakeholders and allowed participation at every step of the process.
- An emphasis on data and evidence-based strategies resulted in a measurable cancer plan and a clear strategy for monitoring progress towards achieving the plan objectives.
- Evaluating every step of the process is needed to determine its success and efficacy.

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RESEARCH & PRACTICE

Evaluating the Needs of Cancer Survivors through Focus Groups and Surveillance Data

Introduction

Cancer is the second leading cause of death in the United States, therefore, much of the research focuses on its prevention and treatment. As these prevention methods and treatments improve, the survival rates for most cancers continue to rise. The American Cancer Society (ACS) estimated that there were 526,100 cancer survivors in the state of Michigan in 2016 (American Cancer Society [ACS], 2016). A person is considered a cancer survivor from the time of diagnosis through the duration of his or her life (ACS, 2016).

Unfortunately, many post-treatment cancer survivors have an array of ongoing mental and physical health needs due to their cancer or its treatment. Many of these needs can be addressed through public health interventions that concentrate on tobacco use (National Cancer Institute [NCI], 2014), physical activity, nutrition (Rock et al., 2012), and emotional well-being (Salvatore, Ahn, Jiang, Lorig, & Ory, 2015), which can help cancer survivors live longer and increase their quality of life. When assessing and planning for the needs of the cancer survivor population, it is important to note that this population tends to be older; in 2014, 88.2% of all cancers diagnosed in Michigan were in people 50 years of age or older.

Public health has typically emphasized prevention and early detection, while the medical community has focused on treatment. Therefore, the ongoing needs of post-treatment cancer survivors are often overlooked. It has become essential for states and researchers to examine the public health needs of this growing population to promote their quality of life. In Michigan, data from the Michigan Cancer Surveillance Program (MCSP) and the 2015 Michigan Behavioral Risk Factor Survey (MiBRFS) in conjunction with cancer survivor focus groups were used to assist public health professionals understand the mental and physical health issues within this population.

Methods

Review of Existing Data. The MCSP is a central Cancer Registry that was established by state law (Act 82 of 1984) to collect reports on cases for in situ and invasive malignancies diagnosed throughout the state. The Cancer Registry provides a basis for cancer surveillance. Data on cancer incidence and mortality are available for the years 1985 to 2014 (Michigan Cancer Surveillance Program [MCSP], 2018).

The MiBRFS is an annual statewide phone survey of Michigan adults aged 18 years and older coordinated with the Centers for Disease Control and Prevention (CDC). It includes a standard questionnaire, which states can customize to target and collect data from specific populations. In 2015, the Michigan Department of Health and Human Services (MDHHS) Cancer Prevention and Control Section's Cancer Survivorship Program added a cancer survivorship module to the MiBRFS that consisted of 13 questions. Prevalence of cancer survivorship was defined as *ever being told by a doctor, nurse, or other health professional that you had skin cancer or any other type of cancer*. For those who were identified as a cancer survivor during the survey, the survivorship module was administered. The module included questions about treatment, post-cancer care, participation in clinical trials, and pain. The results of these questions were used to determine the prevalence of cancer survivors and analyze

relevant characteristics of this population. Additional analyses were performed using questions from the core questionnaire to better understand the behaviors and physical and mental health amongst cancer survivors. Prevalence estimates and 95% confidence intervals were calculated using SAS-Callable SUDAAN (version 11.0.1) (Michigan Behavioral Factor Surveillance System [MiBRFSS], 2018).

Cancer Survivor Focus Groups. To increase the scope of understanding about challenges survivors face, focus groups were conducted. To assist in the development of these focus groups, cancer experts were recruited from the Michigan Cancer Consortium Cancer Survivorship Workgroup membership roster. This group brainstormed potential needs of cancer survivors which were then categorized to identify overall themes for use in the cancer survivor focus groups.

Seven cancer survivor focus groups were held: four urban groups from Ann Arbor, MI, one rural group from Traverse City, MI, and two rural groups from Cadillac, MI. These locations were selected based on previously existing MDHHS contracts addressing cancer survivorship.

The contracted health systems were instructed to recruit survivors who were post-treatment, although length of time since treatment was not a consideration. The groups were open to anyone who had been diagnosed with cancer in their lifetime and had completed initial treatment, or who were receiving long term treatment for cancer. Participants included both white and African American survivors, however; because of the size of these groups it was determined that comparisons by race could not be made. Focus groups had between two and ten participants and were not recorded but were conducted with two note-takers. The focus groups included four activities and were coded for themes. See Table 1 for information on each activity.

While the MiBRFS, MCSP, and focus groups, are three distinct data resources which are independent from one another each one provides a different perspective on cancer survivorship. The subsequent analysis examines how these resources can complement each other and enhance the understanding of cancer survivorship. Conclusions were drawn by noting where the quantitative data can supplement the qualitative data gained from the focus group and where these data resources provide unique information.

Results

Cancer is the second leading cause of death in Michigan with 20,347 Michigan residents dying from cancer in 2015. In 2014, there were 438.2 new diagnoses of cancer per 100,000 Michigan residents, totaling 52,704 new cases of invasive cancer. From 1985 to 2014, 86.4% of cancer patients in the registry had only one cancer diagnosis. For all cases diagnosed in 2005, the Cancer Registry reports a 64.1% survival rate. In the 2015 MiBRFS, 10.0% of Michigan residents age 18 and older reported ever being told they have cancer. *Table 2* shows demographics for the age-adjusted cancer survivor population in Michigan. Among MiBRFS respondents, 38% reported being first diagnosed with cancer at age 60 or older. In comparison, the Cancer Registry reports 68.6% of cases who were diagnosed in 2014 were diagnosed at age 60 or older. The MiBRFS and the Cancer Registry provide essential resources when reviewing cancer survivorship, however they have limitations in terms of the data that they provide. The discrepancy between the Cancer Registry and MiBRFS sources are likely due, in part, to survivor bias. The MiBRFS only surveys people who are alive and healthy enough to complete the phone interview and does not accept proxy responses. Because of this, the needs of severely ill or

disabled survivors may not be captured in these data. Additionally, the MiBRFS asks for the age of the first cancer diagnosis and some respondents may have had a second diagnosis at a later age.

Statistical differences were seen in cancer survivorship among subgroups including: gender, race, education, and employment. Among MiBRFS respondents, 10.9% of females and 9.3% of males reported being cancer survivors. Non-Hispanic Blacks had the lowest percentage of cancer survivors (5.4%) compared to non-Hispanic Whites (11.0%), and Other and multiracial respondents (6.9%). Results for Hispanics or Latinos were suppressed due to having too few respondents. Significant differences existed in employment status; 12.6% of non-working individuals reported being a cancer survivor compared to 10.5% of employed individuals.

Three major themes were identified from the focus groups based off responses to specific questions: health care, health-related behaviors, and social/emotional support; three sub-themes related to health care needs were then identified and are shown in *Figure 1*. Where available, MBRFS prevalence data was compared to these focus group themes.

The first theme relates to the survivors' experiences in seeking a physician post-cancer; cancer survivors are often seen by more than one physician for their medical care. According to the MiBRFS, 51.9% of survivors reported receiving any type of instructions on where to go for post-cancer care, and 40.5% of survivors had those instructions given to them as a written summary. With just over 50% of survivors reporting receiving follow-up instructions, it is not surprising that focus groups survivors reported being unsure of what questions to ask which doctors. Survivors reported that, at times when they would ask a doctor a question, they would be told to ask a different doctor their question. Supportive and understanding medical care staff were viewed as important by the focus groups for improving the medical experience for all survivors.

The second health care theme centered on the primary care provider's ability to properly care for cancer survivors. In the MiBRFS, 84.0% of cancer survivors reported seeing a physician for routine care within the last year. This is important as 29.9% of survivors reported their general health as poor. Among cancer survivors who were at least three months post cancer treatment, 58.8% reported they receive their primary care from a Primary Care Physician (PCP). Those who did not see a PCP reported seeing an oncologist, surgeon, or another type of physician for their primary care. In the focus groups, survivors noted their PCP was not always aware of current screening practices and long-term effects of cancer treatments. The third health care sub-theme centered on finances. In the MiBRFS, 10.3% of cancer survivors reported that they needed to see a doctor but could not because of cost and 19.8% of cancer survivors reported that they were paying medical bills related to their cancer treatment over time. This question was not asked in the 2015 MiBRFS. Focus group participants reported that insurance did not always cover treatment for side-effects and that medical bills and copays were a challenge to pay. Some survivors simply reported that they needed money, with no qualifications about the underlying need for the money. Medical bills and disputes with insurance companies over cancer treatment coverage were also cited as a source of stress that survivors believed interrupted the healing process.

Nutrition has long been a prime focus for public health interventions. Experts recommend that everyone eat at least five servings of fruits and vegetables per day. In the MiBRFS, only 15.9% of cancer survivors reported eating at least five servings of fruits and vegetables every day. Adopting healthy behaviors post-cancer was also a theme in the focus groups. Education on proper nutrition and what to eat to stay healthy was one need identified by survivors. Suggested

nutritional-related resources mentioned by the focus groups included meal delivery and nutritional resources tailored to cancer survivors.

The promotion of physical activity is another area common to public health. However, in the MiBRFS, 42.0% of cancer survivors reported being limited in activities due to a physical, mental, or emotional problem and 34.3% had a Body Mass Index classified as obese. The loss of common activities (e.g. golf) was a concern for some focus group participants. Cancer survivors in the focus groups were interested in resources for things like rehabilitation, adapted exercise classes, and complementary therapies (e.g. yoga and massage) to assist them with staying engaged with favorite leisure activities or to improve their health. *Figure 2* provides the prevalence of these health-related behaviors among cancer survivors.

From the MiBRFS, 11.3% of cancer survivors report having poor mental health (*Figure* 2). All the focus groups discussed the need for additional social and emotional help. Survivors discussed not only body image issues, but the need for help with depression from loss of work, issues around identity, and self-image. Additionally, all focus groups discussed fear of cancer recurrence as a major source of anxiety. Support groups with other cancer survivors who are post-treatment were identified as a resource that could be helpful in addressing mental health issues. Individual counseling was another suggested resource. Family support was also discussed with many survivors stating that cancer is a family disease that can change a family dynamic and cause caregiver fatigue. As seen in our focus group, mental health support is a large need amongst the cancer survivor population and their families; however, quantitative data on this topic is limited because these needs are too specific for a general population surveillance system.

There were issues discussed in focus groups that are currently not measured by a surveillance system. For example, sexual function was a very common theme. Some of this related to changes in body image and some of it related to changes in body function. This demonstrates the importance of combining surveillance activities with activities like focus groups to understand the full range of cancer survivor needs.

The focus groups demonstrated a difference between urban and rural participants. While rural survivors only mentioned transportation as a concern when they had to travel several hours for second opinions, urban survivors mentioned transportation was an ongoing concern due to high traffic in urban areas. Rural groups also reported greater concerns around PCP training in regards to post-cancer care than the four urban groups.

The importance of surveillance data was demonstrated by the fact that smoking was never brought up amongst survivors in the focus group. However, smoking prevalence is a common public health concern for those working within the cancer survivor community. From the MiBRFS, the prevalence of smoking among cancer survivors has decreased from 19.0% in 2011 to 12.3% in 2016 (data not shown). In 2015, 71.3% of cancer survivors who were current smokers reported they had been advised or referred to resources to stop smoking.

Conclusions

The availability and usefulness of surveillance data in cancer survivorship has often been overlooked. Surveillance data on cancer survivorship can assist us in understanding the population and measuring the impact of public health interventions. However, surveillance has some limitations. First, there are questions that are not appropriate for a telephone survey (i.e., sexual functioning). Second, due to the number of people interviewed who report a history of cancer (N=1,433), some results from questions specific to survivorship cannot be analyzed

because there are too few respondents. The small sample size of cancer survivors is also an issue when trying to examine disparities amongst certain sub-populations. Given these limitations, it is important to seek the direct input of cancer survivors through activities like focus groups.

By including cancer survivors in the discussion surrounding their own needs, public health organizations can ensure that their programs are more successful by encompassing important survivorship concerns that may not have emerged in typical surveillance sources. This will become increasingly important as the number of survivors grow. Questions that cannot be asked in a typical survey, such as sexual functioning, can often be overlooked in public health initiatives as there is limited data. Therefore, it is imperative that providers and public health professionals use not only the data available to them, but also the experiences of survivors to have a more complete outline of the public health need.

In 2012, the Michigan Cancer Consortium, the Michigan Department of Health and Human Services, and the Michigan Oncology Quality Consortium started a public health intervention to decrease the prevalence of smoking in cancer survivors. Through a policy and system change model, oncologists now refer their patients who smoke to cessation services. Data obtained from the Michigan Behavioral Risk Factor Surveillance System demonstrates that there has been a statistically significant reduction in the number of current smokers in our survivor population (2011 to 2015) (data not shown). The success of this intervention suggests that other coordinated initiatives should be identified to frame other public health topics.

There are many ways that surveillance data can assist public health agencies in understanding cancer survivor needs. This is especially important because, as expressed from the focus groups, this growing group of cancer survivors often feel that their needs are still unmet. One of the most consistent messages that came out of the focus groups was appreciation for the focus group itself. As a whole, the focus group participants reported that "no one ever asks us what we need". Therefore, it is crucial that public health professionals should not merely analyze data, but also seek the input of the communities which they serve, especially in areas that are not adequately assessed through surveillance measures.

It should be noted that survivorship is experienced differently by all survivors. However, due to small numbers in some populations, comparisons between specific demographic groups cannot be made with the data from the Michigan Behavioral Risk Factor Surveillance System. As the survivorship module questions are asked in the coming years, results will be combined with the data reported in this paper to give a better understanding of how survivorship is experienced by various populations. Conclusions and comparisons regarding how survivorship is experienced by different races were also limited in the focus groups. Survivors were recruited by currently contracted health systems who were limited in their recruitment due to the demographics that they serve. Additional focus groups will be necessary to understand how race may impact survivorship.

Using a wide-range of data, providers and public health workers can continue to address cancer survivor needs throughout the cancer-care continuum. The need for public health programming and provider interventions surrounding cancer survivorship will continue to grow as the population of survivors increases. By using surveillance data, along with focus groups, public health organizations can more accurately target the needs of their survivorship program participants and measure programmatic outcomes.

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Table 1: Summary of Survivor Focus Group Activities

	Activity 1: Ice Breaker	
Prompt given:	Methods:	Outcome:
Who lives in your household?	Verbal	Number of household members
Name one activity you like to do	Verbal	Not recorded
in your free time.		
	Activity 2: Now vs. Then	
Prompt given:	Methods:	Outcome:
Thinking about your cancer	Focus group members were	Identify reoccurring themes and
diagnosis, think of three words	asked to write on index cards	ideas.
that describe something that is	for moderator to collect.	Note any disagreements.
different now as a cancer survivor	Moderator wrote down all	
versus before your diagnosis.	words on the board.	
	Activity 3: Needs	
Prompt given:	Methods:	Outcome:
Thinking about your experience	Focus group members were	Identify reoccurring themes and
as a cancer survivor, think about	asked to write each need on a	ideas.
the kinds of things you need now.	sticky note and categorize	Note any disagreements.
	them under a theme.	Note needs that do not fit in
	Themes were previously	any of the pre-identified
	identified by cancer experts	themes.
	and included: educational	
	needs, health care needs,	
	financial needs, resources,	
	assessment needs,	
	social/emotional, physical	
	needs, new needs, other.	
	Activity 4: Surprises	
Prompt given:	Methods:	Outcome:
We are now going to focus on	As a group, members were	Identify needs that were not
things about cancer that have	asked to identify 15 things that	mentioned in the previous
surprised you. What things have	were surprising.	activity.
surprised you about being a		Note agreements or
cancer survivor?		disagreements about surprises.

Table 2: Characteristics of Participants from the 2015 Michigan Behavioral Risk Factor Survey who reported being a cancer survivor (Age-Adjusted)

Cancer Survivors ^a	Percent	95% Confidence Interval
Overall Michigan	10.0	(9.4, 10.6)
Female	10.9	(10.0, 11.8)
Male	9.3	(8.5, 10.2)
Non-Hispanic White	11.0	(10.3, 11.8)
Non-Hispanic Black	5.4	(4.2, 6.9)
Hispanic or Latino ^b	Suppressed	Suppressed
Other and multi-racial, non-Hispanic	6.9	(4.7, 10.0)
ess than \$20,000	9.9	(8.2, 11.9)
\$20,000 to \$34,999	10.1	(8.6, 11.8)
\$35,000 to \$49,999	10.8	(9.1, 12.9)
\$50,000 to \$74,9999	9.8	(8.4, 11.3)
\$75,000 or more	10.9	(9.7, 12.2)
ess than high school diploma	7.5	(5.7, 9.9)
High school diploma or GED	9.4	(8.4, 10.4)
Some college or Trade School	10.8	(9.7, 12.0)
College graduate or higher	11.4	(10.4, 12.5)
Employed	9.5	(8.2, 11.1)
Unemployed	10.2	(7.2, 14.2)
Non-working	11.9	(10.6, 13.2)
Married	10.7	(9.8, 11.7)
Formerly married	9.3	(7.4, 11.6)
Never married	8.3	(6.3, 10.9)
Widowed	15.8	(11.0, 22.3)
/eteran	11.3	(9.1, 14.0)
Homosexual or Bisexual	11.1	(6.9, 17.3)
18 to 39 ^{c,d}	2.0	(1.4, 2.7)
40 to 54 ^{c,d}	7.2	(6.1, 8.5)
55 to 69 ^{c,d}	18.0	(16.5, 19.7)
70 and Older ^{c,d}	19.4	(14.8, 25.0)

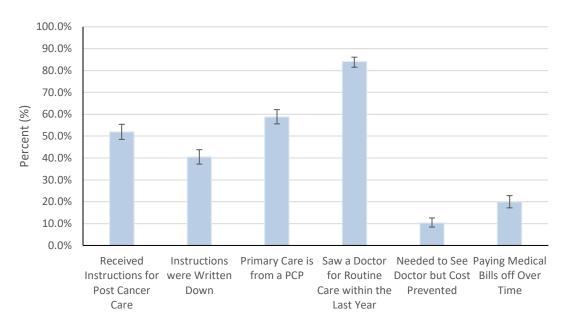
survivor is defined as responding 'Yes' to either "Have you ever been told you have skin cancer" or "Have you ever been told you have any other type of cancer"

^b Prevalence estimate suppressed due to having a standard error of greater than 30%

^c Estimates are not age adjusted

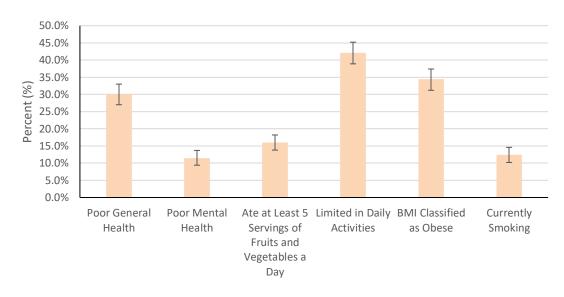
^d Represents the age of the respondent at the time of the survey

Figure 1: Prevalence of Health Care Utilization among Cancer Survivors, 2015 Michigan Behavioral Risk Factor Survey ^a



NOTE: ^a Cancer survivor is defined as responding 'Yes' to either "Have you ever been told you have skin cancer" or "Have you ever been told you have any other type of cancer"

Figure 2: Prevalence of Health-Related Behaviors among Cancer Survivors, 2015 Michigan Behavioral Risk Factor Survey ^a



NOTE: ^a Cancer survivor is defined as responding 'Yes' to either "Have you ever been told you have skin cancer" or "Have you ever been told you have any other type of cancer"