

### ARIZONA CANCER CONTROL PLAN

2020 - 2024





Health and Wellness for All Arizonans

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For more information about Arizona's Cancer Prevention & Control, please visit www.azdhs.gov/cancer.

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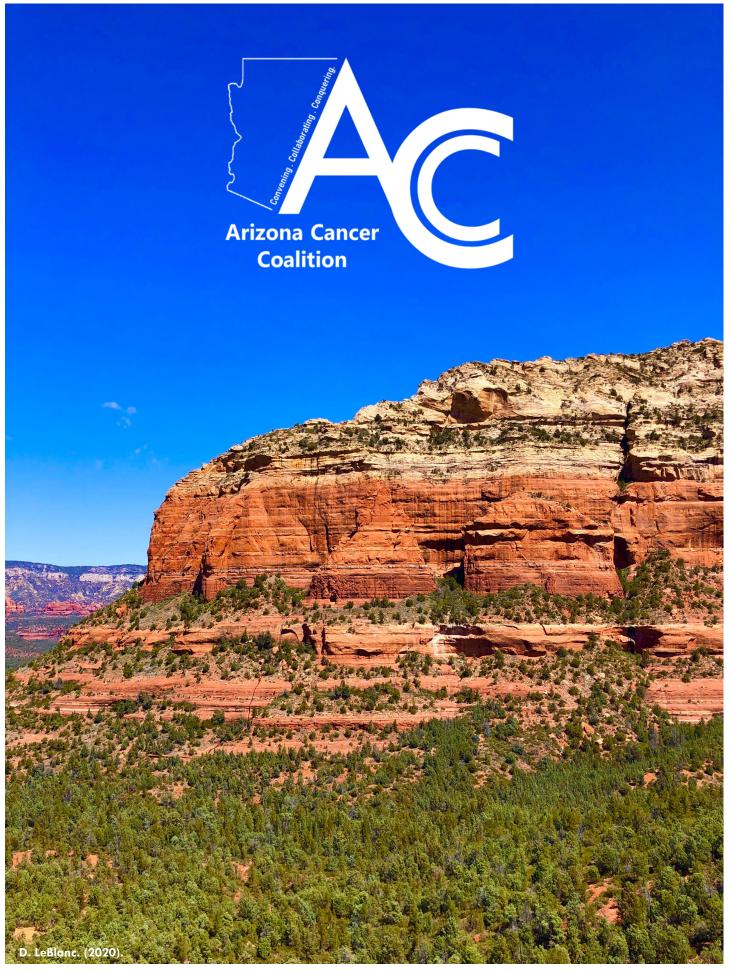
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To My Fellow Arizonans,

We have arrived at a big moment in cancer control in Arizona! With the help of our many partners across the state, strategic actions carried out in the Arizona Health Improvement Plan (AZHIP) and the Arizona Comprehensive Cancer Control Plan, and through advancements in medicine, technology and access to care, we have already surpassed our five year goal, set in 2015, of reducing the cancer mortality rate by more than 5.0%. With a reduction through 2017 of 6.5% (the most recent official count), we have reached a milestone that is nothing short of amazing. Of course, I know you agree that to maintain our progress, we must remain inspired and never take our foot off the pedal in cancer prevention and control.

Cancer remains the second leading cause of death among Arizonans. The American Cancer Society estimates that over 37,000 new cancer cases will be diagnosed in Arizona this year alone. That is roughly 700 new cases per week or 100 new cases per day. Despite these troubling statistics, phenomenal progress is being made across the care continuum. Perhaps our most notable progress is found in the strategies adopted by the Arizona Comprehensive Cancer Control Program (ACCCP), which have helped transform the way health systems, communities and individuals view cancer. In conjunction with the Arizona Cancer Coalition (ACC), our state has developed some of the most effective strategies in the nation for combatting this chronic disease.

As experts in the field and leaders in the community, it is imperative that we address the disparities found within our state that lead to higher rates of disease and death. No matter the race, gender, region or socioeconomic class, each person deserves access to these lifesaving resources. By recognizing that cancer can be addressed on both the individual and population levels, we are empowering citizens to take charge of their health and their futures.

The enclosed document serves as the third edition of the Arizona Cancer Control Plan. It is full of thoughtfully crafted goals, objectives and strategies aimed at reducing the state's cancer burden. These concepts are shared equally across the six action teams of the Arizona Cancer Coalition. Through this work, we hope to provide a roadmap for improving health outcomes by focusing on preventing cancer, increasing early detection, and promoting effective policy development.

Of course, I would like to recognize the many contributors and authors of this document. Without their unwavering support and commitment, neither this plan nor the coalition would be nearly as successful. Among our challenges over the next five years, we look forward to deepening our reach into communities that are particularly vulnerable to those social determinants that too often lead to health disparities that contribute to the cancer burden. With your help, we will continue to show the way to a healthier Arizona.

Sincerely Tery,

Wayne Tormala, Chief Bureau of Chronic Disease & Health Promotions Arizona State Department of Health Services

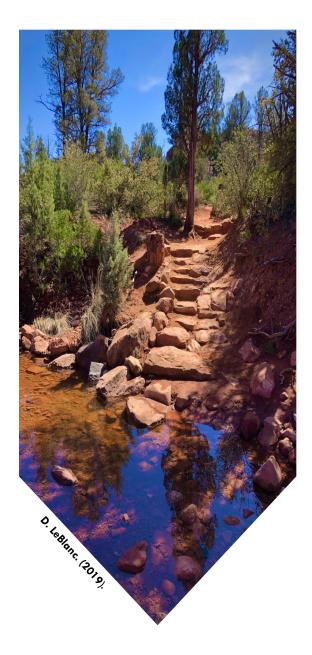
### DEDICATION

This plan is dedicated to the those whose lives have been touched by cancer. Whether a patient, provider, family member or survivor, let this plan serve as tool and a tribute to your incredible spirit.

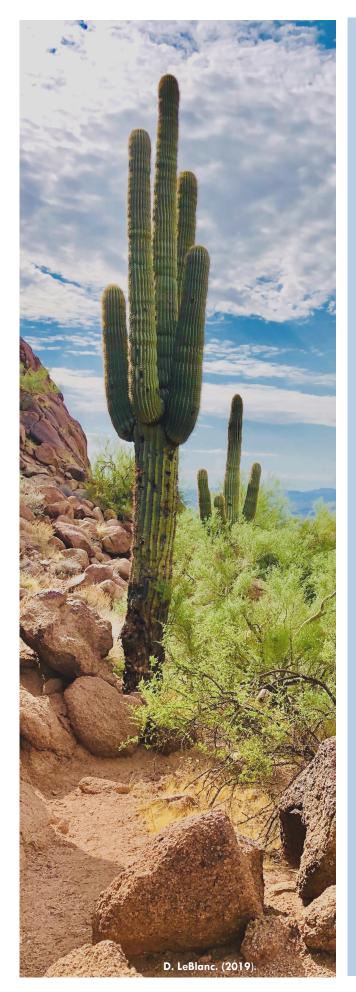


### 2020 - 2024 ARIZONA CANCER CONTROL PLAN

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### **DEVELOPMENT PROCESS**

This plan represents years of discussion, deliberation and collaboration among an extremely diverse and talented group of people. These individuals come from a variety of settings that share in the vision of a cancerfree Arizona. With their invaluable knowledge and expertise, these individuals have come to be known collectively as the Arizona Cancer Coalition (ACC).

For the last 15 years, the ACC has served as a venue for public, private and civic-based organizations to convene and discuss cancer-specific interventions. From the very beginning, the ACC has dedicated itself to championing policies, strategies and evidence-based practices that are proven to decrease the cancer and promote health and wellness.

Planning for the 2020-2024 Arizona Cancer Control Plan began in Fall of 2018 during the coalition's annual ACC Summit. The five work groups and their leads were given the most current cancer data and educated on the most impactful strategies that have been adopted across the globe. With these resources, the groups went straight to work developing the goals, objectives, and strategies that are the foundation of this plan.

After long and thoughtful discussion, the coalition submitted their objectives to the ACC Steering Committee and leadership at the Arizona Department of Health Services (ADHS). These two then organized, refined and published these plans into a comprehensive and colorful plan.

As the coalition continues to evolve and model itself after the national framework, it is the hope of its stakeholders that they can implement a plan that will responsibly utilize time, efforts and resources to make a lasting impact on Arizona's Cancer Community.

### **EVALUATION PROCESS**

An evaluation team from LeCroy & Milligan Associates, Inc. was engaged to monitor process and outcome evaluation measures for the activities within the Arizona Cancer Coalition (ACC).

A comprehensive evaluation plan was developed to measure the 20 objectives determined by the ACC Work Groups. Continuous evaluation of the work and process within the Action Teams, Steering Committee, Core Team and the ACC as a whole guides the coordination of work being conducted throughout Arizona and ensures activities are focused, effective, and aligned with statewide objectives.

The evaluation team provides support to the Steering Committee and Work Groups by assisting with planning and facilitation of Action Team meetings, identifying the activities of the work groups that align with their work groups' objectives and goals, providing ad-hoc professional development and data analysis technical assistance for work groups' activities and reporting on quarterly progress within work groups' action plans.

In addition, the evaluation team provides expertise and coordination among collaboration opportunities between the Core Team and all components of the Arizona Cancer Prevention and Control Programs. Meetings are assessed based upon their level of effectiveness, collaboration, and quality of leadership.

For additional information about the evaluation team and their processes, please visit www.lecroymilligan.com

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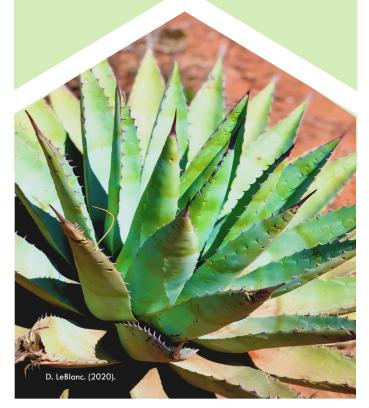


### PART I | THE INTRODUCTION

### **OVERVIEW**

The Arizona Cancer Control Plan is a living document that was made for the people by the people. It represents the coordinated efforts of nearly 100 individuals and 40 organizations from across the state. With the help of experts in the fields of medicine, public health, philanthropy and data science, we are able to provider our readers with a comprehensive plan that outlines Arizona's next steps in the fight against cancer.

In its third edition, the 2020 – 2024 Arizona Cancer Control Plan seeks to accomplish five (5) overarching goals. By addressing these areas, we hope to supply our readers with the knowledge, tools and resources needed to be informed and empowered cancer advocates.





#### **Overview Continued...**

These goals include:

- 1) Highlighting the state's existing cancer burden and underlying health disparities;
- 2) Identifying evidence-based cancer prevention and control activities;
- Developing a coordinated, public health approach to reducing the number of new cancer cases and cancer-related deaths;
- 4) Connecting patients, providers and caregivers to meaningful, cancer-specific resources; and
- 5) Engaging all readers to make the fight against cancer a top priority in Arizona.

For the convenience of the reader, this plan has been divided into four parts. Each part explores a different area of the cancer care continuum while describing goals, objectives, and strategies that we can adopt to move the needle in the right direction for cancer control. And after completing this plan, we hope that each reader has a better understanding of where our state stands and where we hope to go as we strive for a cancer-free Arizona.

### THE ESSENTIALS...

## A Guide to Cancer Control

Before diving head first into this report, we wanted to provide our readers with a brief overview of the commonly used terms and definitions that are featured throughout the plan. Much like learning a new language, cancer terminology takes time to fully understand. And beyond the terms, the charts and graphs featured in this report may be a bit confusing at first glance. To address this, we've included thorough explanations of each exhibit in nearly every part of this report.

Upon completion of this section, you will be able to glide through this report and begin developing your own understanding and ideas around cancer control in Arizona.

## WHAT IS COMPREHENSIVE CANCER CONTROL?

The Centers for Disease Control and Prevention (CDC) defines **Comprehensive Cancer Control** as "a collaborative process through which a community pools resources to reduce the burden of cancer that results in risk reduction, early detection, better treatment, and enhanced survivorship."

Since 1997, the CDC's National Comprehensive Cancer Control Program (NCCCP) has provided funding, guidance and technical assistance to cancer programs across the country to develop, implement, and evaluate state-wide cancer control plans.

Comprehensive cancer control (CCC) plans identify how an organization or coalition addresses the burden of cancer in its geographic area. The plans are specific to each region and based on data collected about people living there. They take the strategies that have worked, either in that region or in a similar place, and make them into a blueprint for action.

The Arizona Cancer Coalition (ACC) is a dynamic group of health providers, insurers, data scientists, philanthropists, public health professionals, and community advocates who convene and collaborate on plans aimed at reducing Arizona's cancer burden. The group is comprised of five primary work groups that focus on a different area of the cancer care continuum. They meet throughout the year to develop and discuss their individualized work plans that are combined and make up the Arizona Cancer Control Plan.

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WHAT IS THE ARIZONA CANCER COALITION?



### WHAT IS HEALTH EQUITY?

**Health equity** is a public health concept that is rooted in equality and inclusion. As defined by the American Public Health Association (APHA), health equity is achieved when every person has the opportunity to attain his or her full health potential and no one is disadvantaged because of social determinants of health (SDOH) such as income, environment, educational attainment or access to health care.

## WHAT ARE POLICY, SYSTEMS, AND ENVIRONMENTAL (PSE) CHANGES?

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**Policy, systems, and environmental (PSE) change** are strategies aimed at improving individual and community-wide health outcomes through complimentary, systems-based goals, objectives and strategies. PSE changes make it easier for individuals to adopt healthier choices. By changing policies, systems and/or environments, communities can have larger impacts on health outcomes such as cancer and other chronic diseases with a relatively small investment of time and resources.

PSE changes can be wide-reaching and highly sustainable when approached and executed correctly. The expansion of the state Medicaid program—Arizona Health Care Cost Containment System (AHCCCS)—in 2015; the systematic collection and reporting of skin cancer data from dermatologists throughout the state; and the addition of sidewalks and bike lanes in rural and suburban communities are all prime examples of impactful PSE change. Ultimately, an effective PSE approach should seek to reach populations beyond its immediate service area and create more sustainable and equitable public health infrastructure.

### WHAT IS THE CANCER CARE CONTINUUM?

The cancer care continuum is a framework developed in the mid-1970s that outlines the various stages of the cancer development and treatment cycle. Below is and example of the continuum as according to the National Cancer Institute (NCI).

### NCI CANCER CONTROL CONTINUUM



### THE ESSENTIALS CONTINUED...

### **Glossary of Terms**

#### **Age-Adjusted Rates**

Age adjustment is a process used to compare incidence and mortality rates over time or among geographic areas or population that have different age distributions. Because most disease rates increase with age, age adjustment eliminates the confounding effect of age when comparing rates. Cancer incidence and mortality is usually expressed in the number of new cases or deaths per 100,000 persons in a population.

#### **Age-Specific Rates**

The rate of incidence or mortality of a specific age group, calculated per 100,000 people.

#### **Best Practices**

A practice supported by a rigorous process of peer review and evaluation indicating effectiveness in improving health outcomes, generally demonstrated through systematic reviews.

#### **Built Environment**

The built environment is defined as the human-made features of our communities. The way we design and build our communities can affect our physical and mental health; in turn designing and building healthy communities can improve the quality of life for all people.

#### **Cancer Burden**

An estimate of the financial, emotional, or social impact that cancer creates within the population. Different racial, ethnic, geographic, and age groups in the United States do not share the burden of disease equally.

#### **Cancer Survivor**

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

#### **Distant Stage**

Cancer that has spread from the primary site to distant organs or distant lymph nodes.

#### **Early Stage**

Early stage combines in situ and local stage using the SEER Summary Stage guidelines.

### **Glossary of Terms**

#### **Evidence Based Intervention (EBI)**

Evidence-based practices are approaches to prevention or treatment that are validated by some form of documented scientific evidence. This includes findings established through controlled clinical studies, but other methods of establishing evidence are valid as well.

#### Federally Qualified Health Centers (FQHCs)

Organizations receiving grants under Section 330 of the Public Health Service (PHS) Act. FQHCs qualify for enhanced reimbursement from Medicare and Medicaid, as well as other benefits. FQHCs must serve an underserved area or population, offer a sliding fee scale, provide comprehensive services, have an ongoing quality assurance program, and have a governing board of directors.

#### **Health Promotion**

Health promotion is the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behavior towards a wide range of social and environmental interventions

#### **Health Risk Factors**

A risk factor is any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or injury.

#### Cancer (In Situ)

Early cancer that is present only in the layer of cells in which it began. There is no penetration of the basement membrane of the tissue.

#### Incidence

The number of newly diagnosed cases of cancer during a specific time period.

#### **Invasive Cancer**

Cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues -- generally, the stage is either "localized," "regional," or "distant."

#### Late-Stage

A term used to describe cancer that is far along in its growth, and has spread to the lymph nodes or other places in the body. Late-stage combines regional and distant stage using the SEER Summary Stage guidelines.

### THE ESSENTIALS CONTINUED...

### **Glossary of Terms**

#### **Localized Stage**

Cancer that is limited to the organ in which it began, without evidence of spread.

#### Mortality

The number of deaths from cancer during a specific time period.

#### **Palliative Care**

Specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family

#### **Patient Navigator**

Patient navigators—a diverse group of lay people and health care professionals who assist patients at all stages of cancer care, from screening and diagnosis to treatment and survivorship.

#### Prevalence

The number of people alive on a certain date who have been diagnosed with cancer at any time in their lives. This is different from incidence in that it considers both newly diagnosed and previously diagnosed people

#### **Quality of Life**

The overall enjoyment of life. Many clinical trials assess the effects of cancer and its treatment on the quality of life. These studies measure aspects of an individual's sense of well-being and ability to carry out various activities.

#### **Regional Stage**

Cancer that has spread beyond the original (primary) site to nearby lymph nodes or organs and tissues

#### Screening (Cancer)

Cancer screening is looking for cancer before a person has any symptoms. Screening tests can help find cancer at an early stage, before symptoms appear. When abnormal tissue or cancer is found early, it may be easier to treat or cure. By the time symptoms appear, the cancer may have grown and spread. This can make the cancer harder to treat or cure.

#### Stage

Stage provides a measure of disease progression, detailing the degree to which the cancer has advanced.

### **EXECUTIVE SUMMARY**

### "We've all got plans...

Big plans, little plans, and plans for the in between. In a sense, life is a never-ending cycle of plan development and execution. But no matter the person, and no matter the circumstance, no one ever plans to receive a cancer diagnosis.

Cancer, which is the name given to a collection of related diseases, is the **second leading cause of disease**related death in Arizona. Each year, more than 30,000 residents are diagnosed with some form of invasive cancer. In fact, **between 2012 and 2016**, more than **150,000 new cancer cases** were reported in Arizona. Putting that number into perspective, those are enough cases to fill each seat in the Arizona Diamondback's Chase Field Stadium *three times over*!

Needless to say, Arizona has a cancer problem.

If you're reading this, chances are you or someone you know has been touched by this life-altering disease. From patients and providers to caregivers and survivors, the impact of cancer is felt in every corner of our beloved state. And while the burden is heavy, we are here to say you and your loved ones do not have to fight this battle alone.

Cancer prevention and control is a multi-faceted and ever-changing field. It takes a variety of people from a variety of backgrounds to develop and coordinate a plan that appropriately addresses this disease. With the guidance of physicians, researchers, policymakers and community advocates, we can begin to change the way our world views and treats cancer. One of the best ways to rally these people together is with a solid comprehensive cancer control plan.

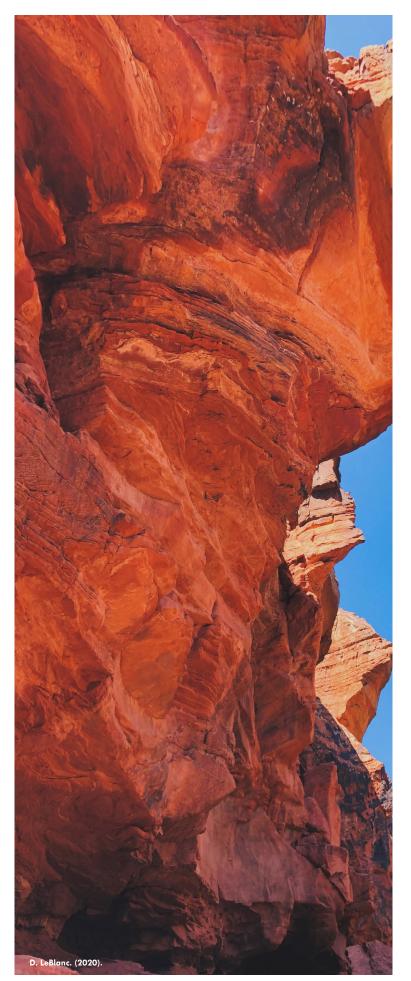
In this profile, you will find the most current data, strategies and insights into Arizona's cancer community. We've enlisted the help of some of our state's brightest and most forward-thinking minds who have dedicated their lives to conquering cancer. Those participating in the planning process set a goal of making this a working document for patients, caregivers, families and survivors. With their knowledge and expertise, we've done our very best to simplify the content and messaging found in this plan. We have also taken the feedback received from other publications and included a glossary, question and answer forum, and resource guide for those looking to use this plan for many years to come. And with that, it is the hope of the Arizona Cancer Coalition and its members that these resources support you through this very sensitive time.

Through constant collaboration, communication and connectivity, we are confident that we can create a better and brighter future for every Arizonan touched by cancer.

-Douglas M. LeBlanc, Jr., MPH

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### PART II | BY THE NUMBERS: ARIZONA'S CANCER DATA

HOW IS ARIZONA'S CANCER DATA COLLECTED?

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The Arizona Cancer Coalition receives its data from a variety of sources to provide the public with the most accurate and up-to -date figures relating to cancer. However, for the sake of this report, its primary source of data is the Arizona Cancer Registry (ACR). Like the Arizona Comprehensive Cancer Control Program (ACCCP), the ACR is also housed at the Arizona Department of Health Services in the Bureau of Public Health Statistics.

The Arizona Cancer Registry is a population-based surveillance system that collects, manages and analyzes information on the incidence, survival and mortality of persons having been diagnosed with cancer. By working alongside hospitals, clinics, physicians, dentists, pathology laboratories, dermatologists, registered nurse practitioners, and ancillary healthcare workers, the ACR is able to collect data on cancer cases to determine site of origin, stage, and a variety of other demographic indicators.

### **CANCER INCIDENCE**

The rate of new cancer is referred to as the **cancer incidence rate**. Many well-known organizations like the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) consider incidence rates among the most reliable measures of a population's health status, and in this case, the population's cancer burden.

The Arizona Cancer Registry (ACR) is a program that collects and analyzes cancer data from reporting sources across the state. The Registry works with hospitals, outpatient clinics, physician offices, pathology laboratories, and an assortment of direct care providers to collect data on each new case. Because the number of cases can vary from year to year, it is very important to identify a specific time frame when determining the incidence rate. The Registry often combines data over a five-year period to give a more accurate picture of the diseases' trend. This method is called **aggregation**.

**Note:** Cancer incidence is represented as a certain number out of 100,000 people. For example, if the lung cancer incidence rate among Arizona women was shown as 40, one could say that a lung cancer diagnosis is likely to occur in approximately 40 out of every 100,000 women in Arizona. This concept is applied to many other cancers and chronic diseases. An exception to this rule would be the measurement of childhood cancer. These incidence rates are measured out of every 1,000,000 children because childhood cancer is much more rare than cancers diagnosed in adulthood. When discussing incidence rates, it is important to remember that the rate does not represent the total number of cases and cannot be used interchangeably with the case count.

Furthering the discussion, **age-adjustment** is a process used to compare incidence and mortality rates over time or among geographic areas or populations that have different age distributions. Because most disease rates increase with age, age-adjustment eliminates the distorting effect of age when comparing those rates.

In Arizona, the **age-adjusted incidence** rate for cancer is **386.7 per 100,000 people**. Compared to the national average of 448.0, Arizona has one of the lowest cancer incidence rates in the nation. While this is relatively good news, it is important to dissect that figure a bit more. Many data scientists and public health experts look at the incidence of specific cancers among different populations and subgroups to gain a more complete picture of the cancer burden.

Cα	Figure 1.1 a Resident Invasive Cancer Inc se Count and Age-Adjusted R II Years Combined (2013-2013	ate,
Dx Year	Case Count	Age-Adjusted Rate
2013 – 2017	1 <i>5</i> 7,377	386.7

Retrieved from the Arizona Cancer Registry on 03/18/2020.

When analyzing cancer incidence rates by race and ethnicity, the inequities become more evident. Of the five primary racial and ethnic groups in Arizona, **Non-Hispanic Whites** have the **highest rate of cancer incidence** (423.0) while Asian & Pacific Islanders have the lowest (231.2). These rates are also representative of the proportion that each race represents in the state. In other words, Non-Hispanic Whites make up the largest percentage of Arizona's population while Asian & Pacific Islanders make up the smallest portion.

Fortunately, the <u>cancer incidence rate has decreased</u> among nearly every racial and ethnic group in Arizona over the last five years. Unfortunately, there has been a slight uptick in cases among Black/African Americans between 2013 and 2017; but because this group only accounts for 5% of the state's total population, the increase in cancer incidence within this group does not heavily impact the state's overall incidence rate.

Of all of the cancer cases that are studied by the Registry, there are five types of cancer that account for the majority of all cases. These include: 1) Female Breast, 2) Lung, 3) Male Prostate, 4) Colorectal, and 5) Melanoma (Skin Cancer). Of the cancers listed, Melanoma is the only type of cancer in our state that ranks above the national average. Due to the state's geographic location and vast desert-like terrain, Arizona sees **26.7 cases of melanoma per 100,000 people** as compared to the rest of the nation at 25.4 per 100,000. Noted, however, efforts by the Arizona Melanoma Task Force have led to increased physician reporting and thus higher case counts and rates. As with many diseases, increased counts/rates are not always a bad thing. It tells us that we are improving our reporting methods and detecting cancers at earlier stages which can help save lives and funding that would otherwise be spent on treatment.

	Figure 1.2   TOP 5 INVASIVE (	CANCER SITES IN ARIZONA
	Cancer Type	Total Case Count (2013—2017)
1	Female Breast	23,694
2	Lung & Bronchus	19,887
3	Male Prostate	16,281
4	Colorectal	13,156
5	Melanoma	9,804

Retrieved from the Arizona Cancer Registry on 03/18/2020.

### CANCER MORATLITY

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Like incidence, cancer mortality (deaths) is among the most reliable tools for determining an area's overall cancer burden. The Arizona Cancer Registry works alongside the Arizona Office of Health and Vital Statistics to gather information about cancer mortality from state-issued death certificates.

The most recent report from ACR shows that **Arizona's age-adjusted cancer mortality rate is 135.1 deaths per 100,000.** Compared to the national cancer mortality rate of 149.1, Arizona maintains a relatively low cancer mortality rate. However, cancer remains the second leading cause of disease-related death in Arizona.

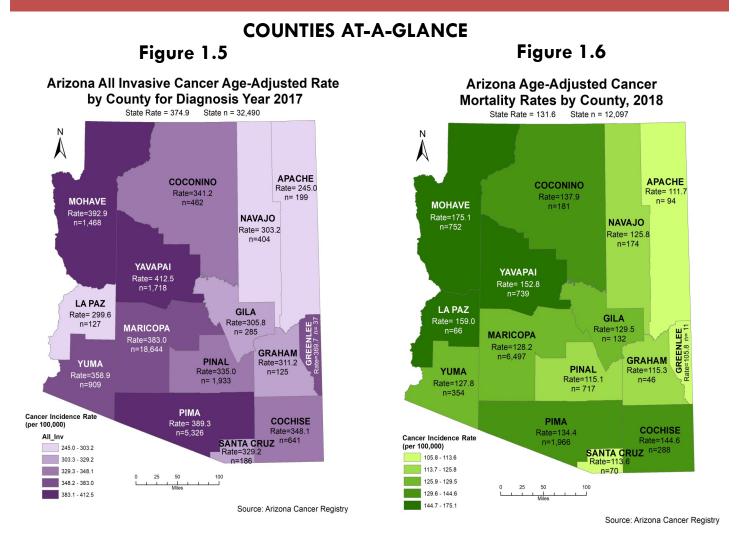
Figure 1.3 Arizona Resident Cancer Mortality: Case Count and Age-Adjusted Rate, All Years Combined (2014-2018)		
Diagnosis (Dx) Year	Case Count	Age-Adjusted Rate
2014 – 2018	58,035	135.1

Retrieved from the Arizona Cancer Registry on 03/18/2020.

### Figure 1.4 | TOP 5 CANCER MORTALITY SITES IN ARIZONA

Cancer Type	Total Case Count (2014—2018)
Lung & Bronchus	13,495
Colorectal	5,233
Pancreas	4,388
Female Breast	4,007
Male Prostate	3,255

Retrieved from the Arizona Cancer Registry on 03/18/2020.



As seen in the graphs above, geography also plays a large role in cancer incidence and mortality.

In 2017, Yavapai County had the highest incidence rate of cancer (412.5 per 100,000) while Apache County had the lowest incidence rate (245.0 per 100,000). In 2018, Mohave County had the highest rate of cancer mortality (175.1 per 100,000) while Greenlee County had the lowest rate (105.8 per 100,000).

For both measures, Mohave County has one the highest cancer burdens in the state. And one would be led to ask "Well, Maricopa County has the most number of cancer cases and deaths, so how is it that Mohave has one of the greatest cancer burdens?"

That is a very valid question. As mentioned before, cancer incidence and mortality rates are calculated by the number of cases and deaths over the total, age-adjusted population in a defined area. Because Maricopa County has a population that exceeds 4 million people and Mohave has a population that is just over 200,000 people, the proportion of people developing and dying from cancer is higher in that area than most others throughout the state. So essentially, while they do not have the highest number of cases, their residents are being affected by the disease at greater rates.

Let it also be noted that the maps above also show a subtle trend that occurs within cancer as well as several other chronic diseases. Arizona's cancer incidence and mortality rates seem to take on a diagonal trend from the northwestern corner down to the southeastern part of the state.

### CANCER STAGING

**Summary staging** is the most basic method of determining how far a cancer has spread from its point of origin.<sup>1</sup> "Early stage" combines persons diagnosed at "in situ" and "local stage" while "late stage" combines persons diagnosed at "regional" and "distant stage."

In Arizona, breast and prostate cancers continue to be diagnosed at earlier stages while lung and colorectal continue to be diagnosed at later stages. Different races/ethnicities are disproportionately impacted by late -stage diagnoses. For more information, please refer to the <u>Arizona Cancer Registry's 2012-2017 profile</u>.

Figure 1.7 Percent of Early/Late Stage* of Arizona Resident Cancer Cases For Selected Cancer Sites (5 Year Aggregate—2013—2017)					
Early/Late Stage	Female Breast	Cervical**	Colorectal	Prostate	Lung & Bronchus
Early Stage	69.7%	44.5%	35.8%	63.7%	22.6%
Late Stage	24.7%	41.1%	51.4%	20.6%	61.9%
Unknown Stage	5.6%	14.5%	12.8%	15.7%	15.5%

\*Early Stage = In situ and Local Stage; Late Stage = Regional and Distance Stage using SEER Summary Stage

\*\*Cervical Cancer Early Stage includes Local Stage Only; In Situ cases are excluded from this data.

1) Young JL Jr, Roffers SD, Ries LAG, Fritz AG, Hurlbut AA (eds). SEER Summary Staging Manual – 2000: Codes and Coding Instructions, National Cancer Institute, NIH Pub. No. 01-4969, Bethesda, MD, 2001.

### CANCER RISK AND CONTRIBUTING FACTORS

When looking at the numbers, Arizona is undoubtedly making progress. We are detecting more cancers at earlier stages while there are fewer cancer-related deaths occurring each year. The data in this section acknowledges cancer once it has already developed. While our Western approach to treating disease may consider this the starting point, more holistic thinking teaches us that there are other factors to consider when discussing disease development and progression.

Along with physical and nutritional health, environmental exposures such as secondhand smoke, poor water quality, and inadequate built environments all play into ones chances of developing cancer. Like much of the nation, beyond its bustling cities, Arizona is a largely rural state with many medically underserved areas (MUAs). In fact, Arizona ranks 40<sup>th</sup> in the nation for primary care provider (PCP) accessibility. This overwhelming shortage of physicians, paired with a steadily growing population, makes it difficult to deliver timely care to the state's most rural populations—populations which typically have lower socioeconomic statuses (SES) and have fewer resources available in their communities.

While 70% of Arizona's residents live in Maricopa and Pima Counties, the remainder are spread across vast landscapes of desert, mountains, farmlands, canyons and tribal reservations. The more rural populations typically have less access to cancer screening and treatment resources thus rendering higher incidence, mortality, and late-stage diagnosis of cancers.

Looking beyond the geographical factors, its is important for chronic disease programs to work together to address the inequalities that exist in our communities. By doing so we can overcome the barriers to care that heavily influence our outcomes.

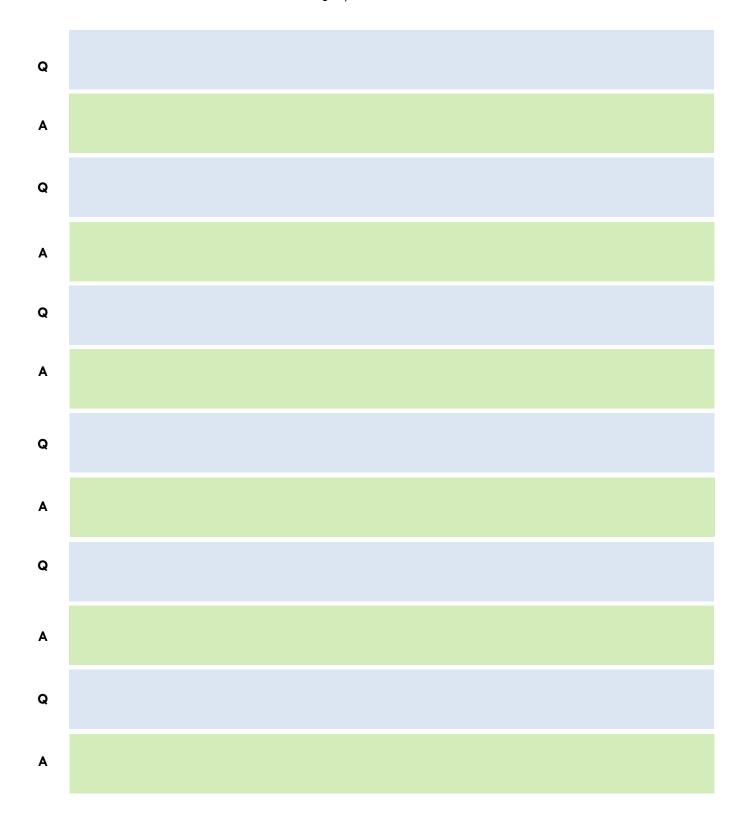
Below is a chart highlighting a few of the most influential factors in the development of chronic diseases such as diabetes, heart disease, stroke, and cancer.

Figure 1.8   CONTRIBUTING FACTORS TO CHRONIC DISEASE IN ARIZONA		
1	According to the American Lung Association, the Phoenix-Mesa metropolitan ar- ea is the <b>seventh (7th) most polluted</b> area in the nation in terms of air quality.	
2	Arizona's Primary Care Physician (PCP) ratio ( <b>125.8 physicians per 100,000 people</b> ) is extremely low when considering the state's rapidly expanding population.	
3	Even with Medicaid Expansion, Arizona's <b>uninsured rate</b> ( <b>10.4%</b> ) is above the national average of 9.8%.	
4	Arizona's <b>smoking rate of 14%</b> is still above the Healthy People 2020 target of 12% for states, tribes and territories.	

Retrieved from America's Health Rankings Report 2019.

### **QUESTIONS YOU MAY HAVE & ANSWERS YOU MAY NEED**

You've taken in a lot of information over these last two sections. While we hope that we've provided you with enough explanation, we recognize that you may still have lingering questions. That is why we've provided this space to list questions that you may have. We also encourage you to reach out to our office or visit us online at www.azdhs.gov/cancer for more information.



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### PART III | THE ARIZONA CANCER CONTROL PLAN



(5) GOALS, (22) OBJECTIVES, (61) STRATEGIES, (1) ARIZONA

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### **EARLY DETECTION & PREVENTION**



### **EARLY DETECTION & PREVENTION**

#### THE ARIZONA CANCER COALITION

#### presents

### Legendary Leaders



Matt Jewett is the Director of Grants at Mountain Park Health Center in Phoenix, Arizona. In his daily work, he oversees a staff of grant specialists who identify funding opportunities for the health system to maintain and expand its services throughout the metro area. He has over 20 years of experience in local politics, education and healthcare management. Matt has been a member of the ACC since 2014 and has served as the Early Detection &Prevention Work Group Co-Chair since 2017.

# 7

### HOW DO YOU DEFINE EARLY DETECTION & PREVENTION AND ITS IMPORTANCE TO CANCER PREVENTION & CONTROL?

<sup>66</sup>Prevention keeps people from having to hear those words: "you have cancer." So many cancers are preventable, and an ounce of prevention is really worth more than a pound of cure. But, we do not know how to prevent 100% of cancers. That is why early detection is so important. For colon cancer, for example, when found early and localized in the colon, the five-year survival rate is 90%. When the cancer is found at a late stage, and has spread to other parts of the body, five-year survival rates are less than 15%. So many cancers have screening tests. Many are quite easy and inexpensive, and virtually all that are worthwhile are covered by insurance. Early detection gives us better odds at finding and treating the disease, greater peace of mind, and less discomfort.<sup>29</sup> - Matt Jewett



### WHAT BENEFIT DOES GENETIC TESTING HOLD FOR PATIENTS AND THEIR FAMILIES?

<sup>66</sup>About 5% to 10% of all cancers are related to inherited changes in DNA (gene mutations) that can be passed down through the family. Genetic tests can look for many of these changes and determine if an individual inherited a gene mutation (or other genetic changes) that puts them at higher risk of developing disease. In addition, genetic tests are beginning to benefit individuals without a family history also. Following the complete sequencing of the human genome in the early 2000s, inherited changes in DNA have been discovered in individuals with no family history of disease putting these individuals at increased risk of developing disease.

Genetic testing gives doctors the ability to personalize preventive and early detection measures in order to decrease a patient's risk and increase the chance of detecting cancer early. In addition to providing patients with important information regarding medical decisions and managing their health care, testing may also be used for personal utility including relief from uncertainty and life planning. Genetic testing for cancers that are passed down through the family has become part of standard of care because of the evidence-based benefits it offers patients. In the near future, this (and other) testing is likely to become standard of care for individuals'—without a family history as well especially considering that some of the inherited DNA changes can impact treatment decisions.

It is important to keep in mind that genetic (and genomic) testing can only tell you if you have a specific gene mutation. A positive test result does not always mean you will get the disease. On the other hand, a negative result does not mean you have no risk of getting the disease. Risk is determined by genetics, environment, or both and can also change over time with age and lifestyle choices. If cancer (or any disease) runs in your family or you have a reason to think you might benefit from testing, talk with you health care provider or a genetic counselor.<sup>29</sup> - **David Duggan, PhD** 



Dr. David Duggan is an Associate Professor at the Translational Genomics Research Institute (TGen), a City of Hope National Medical Center affiliate, in Phoenix, Arizona. With over 30 years of scientific expertise, he has published more than 175 manuscripts, co-edited a book titled Oncogenomics, and has provided consultation services to leading genetic companies and dozens of equity management firms. He currently serves as the Co-Chair of the ACC Early Detection & Prevention Work Group and has contributed his time and talents to the coalition since 2017.

#### NOTES \_

### **EARLY DETECTION & PREVENTION**

Early detection and prevention (ED&P) are among the most effective tools in the fight against cancer. Aside from their practicality and cost-effectiveness, the benefits of ED&P can be seen at the individual, community and societal levels.

Early detection involves the routine screening of age-eligible, high risk, and/or symptomatic individuals for cancers and precancerous lesions. In an effort to detect and treat cancer before it spreads, organizations such as the United States Preventative Services Task Force (USPSTF) and the American Cancer Society (ACS) establish screening guidelines for specific types of cancer.

Primary prevention focuses on actively engaging in risk reduction behaviors such as avoiding tobacco use, eating well, exercising and practicing sun safety. Preventative measures such as these are known to yield positive results for a variety of chronic diseases including cancer. In addition to these, discussing family history of cancers can guide screening recommendations and referrals to genetic counseling.

Of the many components of early detection and prevention, the ACC ED&P Work Group has decided to adopt (1) goal, (6) objectives, and (16) strategies as their own during the 2020—2024 term. Together, these goals, objectives and strategies represent the first part of the new Arizona Cancer Control Plan.

#### **GOAL:** Prevent the initial onset and development of cancer through health promotion and early detection.

Objective	Develop and disseminate at least two (2) evidence-based resources for patients
(1)	regarding genetic testing, counseling and/or public health genomics.

	Strategic Options
1.1	Establish a baseline for the quantity and quality of available resources centered on genetic testing, counseling and cancer genomics in Arizona.
1.2	Convene statewide stakeholders to contribute expertise and content to the development of these new resources.
1.3	Collaborate with primary care practices, clinics, hospitals and cancer treatment centers to disseminate the newly developed materials.



Adobe Stock Photo.

Objective (2)	Increase the percentage of adolescent males and females ages 13-17 that are up to date with the HPV vaccine series from 51.0% (females) and 50.4% (males) to 80.00% (males and females) by June 2024.
Source	CDC TeenVaxView, National Immunization Survey-Teen (2018). <u>https://</u> <u>www.cdc.gov/vaccines/imz-managers/coverage/teenvaxview/data-reports/hpv/</u> <u>dashboard/2018.html</u>

Strategic Options		
2.1	Utilize cross-sector collaborations within clinical and community-based settings that use evidence- based interventions to increase vaccination rates.	
2.2	Utilize health systems-based interventions such as patient reminders, provider reminders, provider assessment and feedback and actively engage in reducing structural barriers.	



CDC. (2018) NCCCP Prevention.

Objective	<b>Decrease</b> the percentage of high school students who currently use <b>electronic</b>
(3)	<b>vapor products</b> by 10% or more from 16.1% to ≤14% by June 2024.
Source	Youth Risk Behavior Surveillance (2017). Percentage of high school students who currently used vapor product—Table 67. <u>https://www.cdc.gov/healthyyouth/</u>



Kenzo Tribouillard—AFP/Getty Images

	Strategic Options		
3.1	Utilize community-wide interventions rooted in tobacco prevention and cessation education among youth.		
3.2	Utilize health systems-based interventions such as patient reminders, provider reminders, provider assessment and feedback and actively engage in reducing structural barriers.		
3.3	Policy-driven collaborations that focus on limiting youth access to traditional and nontraditional tobacco products.		

Objective (4)	<b>Increase</b> statewide <b>colorectal cancer (CRC) screening rates</b> among adults aged 50-75 from <b>67.4</b> % to <b>80</b> % by June 2024.
Source	CDC, BRFSS 2018. Accessed via America's Health Rankings Annual Report <u>https://</u> <u>www.americashealthrankings.org/explore/annual/measure/</u> <u>colorectal_cancer_screening/state/AZ</u>

Strategic Options	
4.1	Utilize cross-sector collaborations within clinical and community-based settings that use evidence- based interventions to increase CRC awareness.
4.2	Utilize health systems-based interventions such as patient reminders, provider reminders, provider assessment and feedback and actively engage in reducing structural barriers.



Adobe Stock Photo.

Objective (5)	<b>Decrease melanoma morality</b> among Arizonans by 10% or more from <b>2.4</b> deaths/per 100,000 people to ≤ <b>2.1</b> deaths/per 100,000 people by June 2024.
Source	Arizona Cancer Registry (2019).



Strategic Options	
5.1	Cross-sector collaborations within state-based and community-based organizations that utilize evidence-based interventions intended to educate and promote sun safety year round.
5.2	Continuous collaboration with field experts and stakeholders to identify policy-driven solutions to reduce Arizona's melanoma mortality rate.

CDC. (2018).

Objective (6)	Decrease the rate of late-stage diagnosis for lung & bronchus cancer from 59.4% to 57.7% by June 2024.
Source	Arizona Cancer Registry (2019).

Strategic Options	
6.1	Utilize cross-sector collaborations within state-based and community-based organizations that use evidence-based interventions to decrease tobacco use and promote cessation.
6.2	Utilize health systems-based interventions such as patient reminders, provider reminders, provider assessment and feedback and actively engage in reducing structural barriers.
6.3	Increase promotion of Low Dose Computed Tomography (LDCT) as a means to screen for lung & bronchus cancers.
6.4	Identify policy-driven solutions to increase tobacco taxes, establish a tobacco retailer registry, limits access to minors, and reduces secondhand smoke exposure.

### EARLY DETECTION & PREVETION

# Work Plan Synopsis

The Arizona Cancer Coalition's Early Detection & Prevention Work Group is dedicated to cancer prevention through sharing consistent cancer prevention messaging, reducing silos among agencies, and building upon shared values of health promotion across disciplines. Through these goals, objectives and strategies, it is the hope of the group and its members that we will begin to see an increase in the adoption of preventative practices and a decrease in the number of cancer-related deaths in Arizona.

#### NOTES \_\_\_\_\_

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# TREATMENT





# TREATMENT

### THE ARIZONA CANCER COALITION

#### presents

# Legendary Leaders



Dr. Abhinav Chandra is the Medical Director of Yuma Regional Medical Center's Cancer Center in Yuma, Arizona. Dr. Chandra's clinical areas of expertise include solid, hematological and gynecological malignancies, lung cancer, and benign hematological disorders. His care philosophy is that physicians should be partners alongside patients and their families, guiding them to consider treatment options based upon their values, preferences and unique concerns. Dr. Chandra has been a member of the ACC for several years and has served as the ACC Treatment Work Group Chair since 2017.

### WHAT DO YOU FEEL IS THE GREATEST OBSTACLE STANDING BETWEEN PATIENTS AND ENROLLING IN CLINICAL TRIALS? WHAT CAN ARIZONANS DO TO INCREASE AWARENESS AND ENROLLMENT?

<sup>66</sup>The greatest obstacles are the investment, bureaucracy and the infrastructure required to run a successful clinical trials program. Hence, most of the clinical trials are limited to large academic centers. Other barriers include skepticism on the part of patients as viewing clinical trials as a method of 'being experimenting upon' them. Clinically, the drug has undergone prior testing and shown promise and hence they are advanced further for subsequent testing.

In Arizona, we need to increase awareness about clinical trials and increase the enrollment. Socially relevant messaging will play an important factor. Also, the ability to have just in time clinical trial coupled with next generation sequence testing as a modality for starting clinical trials early is a lucrative option to consider to increase enrollment.<sup>99</sup> - **Abhinav Chandra**, **MD** 



# TREATMENT

Over the last decade, treatment has revolutionized the way we view cancer. With continuous improvement and innovation in the fields of research, technology, and delivery of care, we have seen a significant decline in the number and rate of cancer-related deaths as well as a rise in survival and improved quality of life.

Cancer survivors, their families and the community have indicated that access to care is the primary, overarching concern in Arizona. Providers have indicated that the vast number of entry points in the cancer continuum serves as a challenge for both them and the patient as they work to ensure coordinated, high quality and timely care from initial diagnosis to the treatment of cancer.

The ACC Treatment Work Group is comprised of partners from Yuma Regional Medical Center, The University of Arizona, Arizona Oncology, the American Cancer Society, and local nonprofits such as Bag It and Cancer Support Community Arizona. Together, this group seeks to ensure a well-prepared, well-resourced cancer care community that stretches from the state's most urban areas to its most rural communities.

**GOAL:** To decrease health care disparities in the state of Arizona and provide timely, quality care.

Object (1)		Establish a baseline to determine the percentage of patients that are successfully navigated to oncology care within seven (7) business days following initial cancer diagnosis by June 2024.*
Sourc	ce	Arizona Cancer Registry (2019).

Strategic Options	
1.1	Identify existing resources and data collection methods that currently support this objective.
1.2	Convene statewide clinical partners to identify, adopt and refine best practices for patient diversion into oncology care.
1.3	Implement continuous quality improvement methods to support quick enrollment and patient follow-up.



# TREATMENT

Objective	Develop and promote the utilization of one (1) comprehensive patient navigation resource
(2)	for patients undergoing cancer treatment by June 2024



Strategic Options	
2.1	Identify existing resources and communication channels specific to patient navigation in the cancer treatment realm throughout Arizona.
2.2	Convene statewide stakeholders to contribute additional resources, content and expertise to the development of a comprehensive patient navigation resource.
2.3	Collaborate with primary care practices, clinics, hospitals and cancer treatment centers to disseminate the resource list.

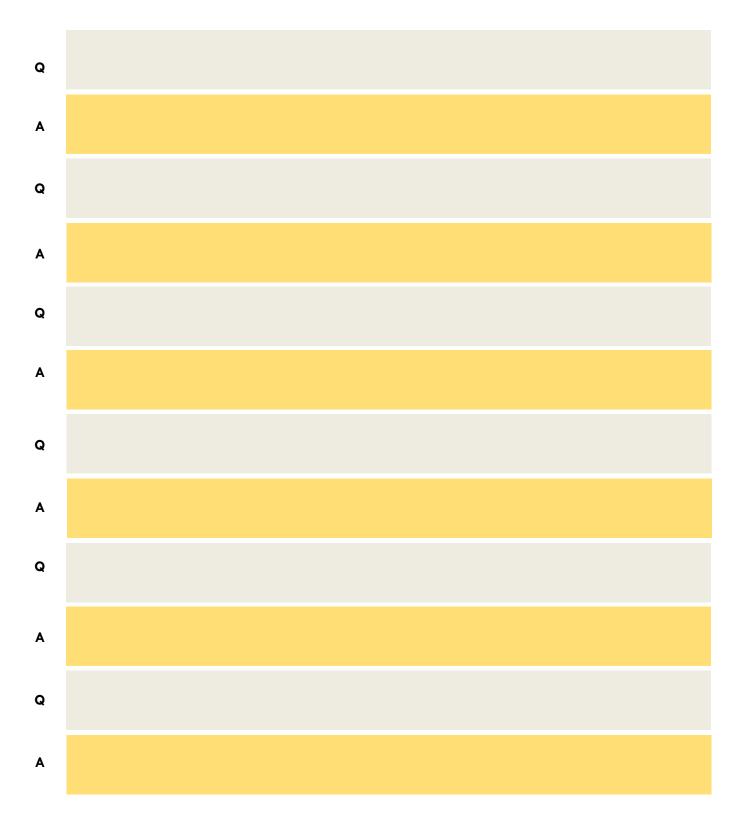
Objective	Increase the proportion of ethnic and racial minorities enrolled in cancer-specific
(3)	clinical trials by June 2024.
Source	Arizona Cancer Research Network (n.d.).

	Strategic Options	
3.1	Establish a baseline to determine the total number of ethnic and racial minorities enrolled in clinical trails throughout Arizona.	
3.2	Educate providers and people diagnosed with cancer on the availability, purpose, and benefits of clinical trials.	
3.3	Promote policy, systems and environmental changes to assess and address barriers to clinical trial participation among target populations.	
3.4	Utilize patient advocates, peer mentors, patient navigators, and representatives of target minority groups to enhance recruitment and retention in clinical trials.	



### **QUESTIONS YOU MAY HAVE & ANSWERS YOU MAY NEED**

This marks the halfway point of the work group goals, objectives and strategies. While we hope that we're continuing to provide you with enough explanation, we recognize that you may still have lingering questions. That is why we've provided this space to list questions that you may have. We also encourage you to reach out to our office or visit us online at www.azdhs.gov/cancer for more information.



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# **SURVIVORSHIP & QUALITY OF LIFE**



# **SURVIVORSHIP & QUALITY OF LIFE**

### THE ARIZONA CANCER COALITION

#### presents

# Legendary Leaders



Dr. Sandi Ernst Perez is the Chief Program Officer for Cancer Support Community Arizona. From the organization's Flagstaff office, she oversees program development, execution and evaluation throughout the Grand Canyon State. With a background in Medical Social Work and Clinical Psychology, Dr. Perez brings over 25 years of business, healthcare and philanthropic experience to the coalition. Her knowledge and insight are invaluable to the ACC where she has served as the Chair of the Survivorship & Quality of Life Work Group since 2018.

# 10

# HOW CAN SUPPORT GROUPS AND SOCIAL INTERACTION IMPROVE QUALITY OF LIFE FOLLOWING A CANCER DIAGNOSIS?

<sup>66</sup>Developments in treatments, medicines, and research are continuing to advance and extend life for people recovering from cancer. While that is tremendously hopeful and encouraging for all of us facing this disease, it is not the whole picture.

In 2008, the Institute of Medicine published a seminal article on the power of psychosocial supports in cancer recovery. If we dissect that word, we see it encompasses the psychological and the social aspects effecting recovery. Taking advantage of our social circle, increasing a sense of hope and optimism, and connecting with people we love are proving to be critical components in how we recover and regain our life beyond a cancer diagnosis.

Those strategies are not always comfortable or easy. Many times, we have never learned how to take care of ourselves emotionally or pay attention to our internal mental wellness. It is unfamiliar territory. But if we are willing to try – we can create a strong internal sense of self and optimize our quality of life, no matter what physical health issues we confront.<sup>27</sup> - Sandi Ernst Perez, PhD



# **SURVIVORSHIP & QUALITY OF LIFE**

The term "cancer survivor" refers to someone living with, through, or beyond cancer from the moment of diagnosis through the end of life. This includes patients who are being treated for cancer, who are free of cancer, and who live with cancer as a chronic condition.

According to a recent report published by the American Cancer Society (ACS), it is estimated that nearly 17 million Americans identify as cancer survivors. That number is up roughly 2.5 million from 2014. And within those 17 million, nearly 393,000 are residents of Arizona.<sup>2</sup>

As with many chronic diseases, cancer survivors have unique medical, psychological and social needs that must be addressed. As this population continues to grow, ensuring that they have the proper care, support and resources in place is becoming increasingly important. Appropriate post-treatment plans can increase independent living among this very special population and positively impact their quality of life.

The Arizona Cancer Coalition's Survivorship Work Group is striving to improve and facilitate access to resources through thoughtful policies, systems and environmental changes. With the help of family members, health providers, and other survivors, significant and lasting change can occur in Arizona's Cancer Community.

#### **GOAL:** To optimize the quality of life for every person impacted by cancer.

Objective	Develop and promote the utilization of common definitions to produce at least one (1)
(1)	cancer survivorship publication by June 2024

Strategic Options	
1.1	Convene statewide stakeholders to contribute expertise and content to the development of a new resource.
1.2	ldentify, adopt and promote common definitions to be compiled into a new resource.
1.3	Collaborate with primary care practices, clinics, hospitals and cancer treatment centers to disseminate the newly developed materials.



Merriam Webster (2016).

2) American Cancer Society. Cancer Treatment and Survivorship Facts & Figures 2019-2021. Atlanta: American Cancer Society; 2020.

# SURVIVORSHIP & QUALITY OF LIFE

Objective	Increase the awareness and utilization of the ACC Survivorship Resource Page through at
(2)	least <b>one (1) media campaign</b> by June 2024.



Strategic Options	
2.1	Establish a baseline for the current utilization of the survivorship webpage.
2.2	Engage stakeholders who can assist in the redevelopment and marketing of the resource page.
2.3	Collaborate with primary care practices, clinics, hospitals and cancer treatment centers to market and navigate patients to the resource.

Objective	Double the percentage of patients who've reported receiving a treatment summary
(3)	plan or survivorship care plan by June 2024.

Strategic Options		
3.1	Establish a baseline for the number of treatment summary plans and survivorship care plans that have been disseminated to cancer patients throughout Arizona.	
3.2	Convene partners to discuss baseline data and best practices for increasing dissemination and utilization.	
3.3	Collaborate with primary care practices, clinics, hospitals and cancer centers to increase overall resource dissemination and reporting.	



Adobe Stock Photo (2018).

Objective	Adopt and implement at least two (2) evidence-based interventions (EBIs) focusing
(4)	on cultural factors within cancer survivorship by June 2024.

	Strategic Options	
4.1	Conduct an assessment of existing interventions that are specific to culturally appropriate cancer care in Arizona.	
4.2	Identify specific subpopulations and interventions that can accompany existing programs and re- sources.	
4.3	Convene stakeholders to promote, implement and evaluate these culturally-tailored EBIs.	

Shutterstock(2014).

Objective	Explore and address the issues created for survivors, the "cautious reality" of living
(5)	with "chronic cancer".



Strategic Options		
5.1	Establish a baseline of available resources centered on the "cautious reality" of living with chronic cancer that may exist. Develop a needs assessment to accompany this task, if necessary.	
5.2	Convene statewide stakeholders and cancer survivors to contribute their lived experiences, knowledge, and insight to the ongoing conversation.	

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### THE ARIZONA CANCER COALITION

#### presents

# Legendary Leaders



Brian Hummell is the Arizona Government Relations Director for the American Cancer Society Cancer Action Network (ACS CAN). For the last decade, Mr. Hummell has championed local and statewide policies aimed at improving Arizona's cancer care continuum. Aside from cancer-specific legislation, Mr. Hummell dedicates a great deal of time advocating for health equity, food security, and tobacco control causes. He was named the Chair of the ACC Policy Work Group in 2011 and continues to serve in that capacity.

## WHAT WOULD YOU CONSIDER THE GREATEST LEGISLATIVE ACCOMPLISHMENT IN ARIZONA FOR CANCER CONTROL?

<sup>66</sup>I would consider one of the greatest cancer-specific policy changes in Arizona to be the 2012 state Medicaid policy change that allowed treatment for women who would have qualified for the National Breast and Cervical Cancer Early Detection Program (in Arizona known as the Arizona Well Woman HealthCheck Program), but were screened elsewhere. As a result of that change, more than (500) women who would have struggled to find treatment options, received life-saving treatment for their breast or cervical cancer diagnosis.

As important as that is, that policy success was integral in the passage the following year for restoring and expanding Arizona's Medicaid program. That policy change granted access to medical care for literally hundreds of thousands of Arizonans, and we know that outcomes are significantly greater for people who have access to health care coverage.<sup>99</sup> - **Brian Hummell** 



Behind every great change is a well-crafted policy. Every day, legislators at the local, state and national levels are making decisions that affect cancer patients and their families. It is critical that lawmakers know how their decisions on issues such as access to health care, the cost of pharmaceuticals, and the funding of screenings and treatment programs impact the lives of cancer patients everywhere. Additionally, decisions on investments in research, tobacco control and prevention policies all play a role in how we prevent, treat and control cancer.

Each year, the American Cancer Society Cancer Action Network (ACS CAN)-one of the largest cancer advocacy organizations in the country- publishes a national report card for each state on policies that impact the cancer community. In it's most recent report, Arizona made exceptional progress in the areas of increased access to Medicaid, increased cigarette tax rates, and the implementation of comprehensive smoke-free laws. However, the state has a lot of ground to cover in the areas of access to palliative care and indoor tanning restrictions.

The Arizona Cancer Coalition Policy Action Team seeks to shape rules, regulations, and policies with input from organizations and communities, and to increase awareness of the positive impact policy change can have on health outcomes.

**GOAL:** To provide for Arizona's cancer community through education, legislation and community mobilization.

Objective (1)	Increase the number of organizations that have taken the National Colorectal Cancer Roundtable's (NCCRT's) 80% in Every Community pledge to make CRC prevention & control a priority from 28 to 50 by June 2024.
Source	National Colorectal Cancer Roundtable (2020). Retrieved from <u>https://nccrt.org/state/arizona/</u>

	Strategic Options	
1.1	Utilize supporting strategies to increase awareness of the 80% campaign as well as CRC screening options and prevention methods.	
1.2	Collaborate with primary care practices, clinics, hospitals, treatment centers, state agencies, philanthropic and faith-based organizations to raise awareness and secure pledges.	National Colorectal Cance

er Roundtable (2019).

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Objective (2)	Secure legislative support to sponsor at least (1) bill that would expand CRC screening eligibility to those aged 45-49 by June 2024.
Source	Arizona State Legislature.

Strategic Options		
2.1	Promote policy and system changes at the local and state levels that encourage the screening of high risk individuals for CRC.	
2.2	Increase the number of educational opportunities supporting this issue among legislators and community members.	NATIONAL Colorectal Cancer ROUNDTABLE
2.3	Collaborate with primary care practices, clinics, hospitals, treatment centers, state agencies, philanthropic groups and faith-based organizations to raise awareness and increase advocacy surrounding the issue.	NCCRT (2020).

Objective	Maintain level-funding for Arizona's Breast & Cervical Cancer Screening and	
(3)	Treatment Programs as well as the Arizona Cancer Registry through FY 2025.	
Source	Arizona State Legislature.	



Well Woman HealthCheck Program.

	Strategic Options		
3.1	Highlight the physical and financial community benefit of Arizona's Cancer Screening ,Treatment, and Surveillance Programs.		
3.2.	Collect patient and provider testimonials to include in advocacy campaigns.		

Objective (4)	Continue to <b>garner legislative support</b> to sponsor at least (1) bill that would prohibit the use of indoor tanning devices by minors by June 2024.
Source	Arizona State Legislature.

	Strategic Options	
	4.1	Promote policy and system changes at the local and state levels that discourage the use of indoor tanning devices by minors.
	4.2	Increase the number of educational opportunities supporting this issue among legislators and community members.
Skin Cancer Foundation. (2015).	4.3	Collaborate with primary care practices, clinics, hospitals, treatment centers, state agencies, philanthropic groups and faith-based organizations to raise awareness and increase advocacy surrounding the issue.

# Work Plan Synopsis

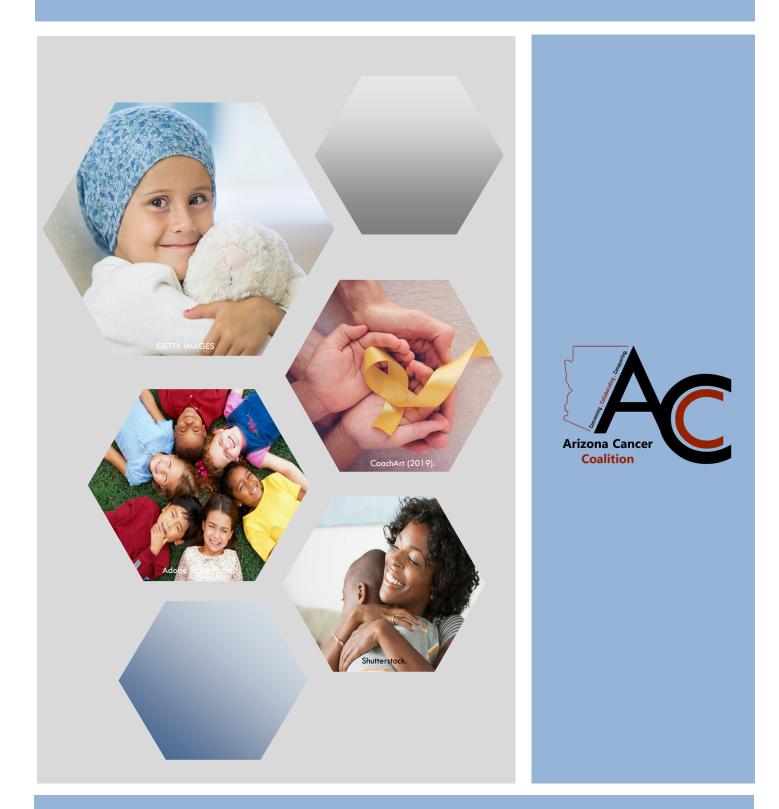
The Arizona Cancer Coalition's Policy Work Group seeks to shape rules, regulations and policies with input from organizations and community stakeholders who have been both directly and indirectly impacted by cancer. In doing so, the group hopes to increase awareness of the positive impact policy change can have on health outcomes. And, most importantly, the group hopes to foster the next generation of cancer advocates who champion impactful and sustainable policies.

#### NOTES \_

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# CHILDHOOD CANCER



# CHILDHOOD CANCER

### THE ARIZONA CANCER COALITION

#### presents

# Legendary Leaders



Dr. Alexandra Walsh is a pediatric oncologist with the Center for Cancer & Blood Disorders at Phoenix Children's Hospital in Phoenix, AZ. Here she works with a multidisciplinary team of physicians, nurses, case managers and researchers to provider the highest quality of care to pediatric cancer patients and their families. In addition to this, she also serves as the Director of the Long Term Follow-Up Clinic for Pediatric Cancer Survivors at PCH. She co-chairs the ACC Childhood Cancer Workgroup with Mrs. Patti Luttrell.

### WHAT ARE YOUR GO-TO TALKING POINTS ABOUT CHILDHOOD CANCER WHEN YOU ARE ADVOCATING FOR PATIENTS, FAMILIES AND PROVIDERS?

<sup>66</sup>Overall survival for childhood cancer is 85% and we continue to make incremental progress. However, the diagnosis of childhood cancer is extremely stressful on not only the family but the entire community. We need more resources to support patients and survivors and their families, as well as more money for research to continue to improve our survival rates.<sup>27</sup> – Lexa Walsh, MD



### WHAT IS THE FIRST PIECE OF ADVICE THAT YOU WOULD GIVE A PARENT, CAREGIVER OR FAMILY MEMBER OF A RECENTLY DIAGNOSED CHILDHOOD CANCER PATIENT?

<sup>66</sup>Few things in life are as devastating as hearing those words, "Your child has cancer." There can be an overwhelming sense of confusion, anxiety, and fear during those first days and weeks after receiving the diagnosis. Open, honest two-way communication between you and your healthcare team is important. Make sure you are comfortable with the information you are receiving. Your healthcare team needs your active participation, including asking lots of questions. Some tips that may be helpful related to communication include:

- 1) Keep paper and a pencil nearby to write down notes and questions.
- 2) Write questions down as you think of them so you are prepared when your health care team is available.
- 3) Ask a second adult to attend appointments together with you. This offers a "second set of ears" to confirm the information presented during the meeting when stress and anxiety may prevent you from retaining information.
- 4) Ask if you don't understand something. The only silly question is an unasked question.
- 5) Ask for help with communication if needed. Interpreters can be helpful if there is a language barrier.
- 6) Repeat key points to ensure understanding.

Navigating this cancer journey can be stressful and challenging, but open, honest two-way communication with your healthcare team can provide a strong foundation. Throughout the journey,

know that your health care team is there to support you and your child through this difficult time."

- Patti Luttrell, RN, MS



Mrs. Patti Luttrell is a licensed pediatric nurse and mother of a long-term childhood cancer survivor. She is also the co-founder and Executive Director of Children's Cancer Network (CCN). With over 30 years of experience, Mrs. Luttrell brings extremely valuable pediatric nursing, healthcare management, program development, and nursing education to the field and her community. She currently serves as the co-chair of the ACC's Childhood Cancer Work Group alongside Dr. Lexa Walsh.

NOTES

# CHILDHOOD CANCER

Childhood cancer remains a top priority for Arizona. Early diagnosis of childhood cancer can be challenging because symptoms are similar to those of more common childhood illnesses. Thankfully, improvements in detection and care have led to significant increases in the number of patients who survive their diagnosis. Furthermore, mortality rates of childhood cancer have declined over the past four decades thanks to improvements in treatment and high rates of participation in clinical trials.

Experts recommend that pediatric cancer patients be treated at medical centers with multidisciplinary teams that specialize in childhood cancer. Pediatric cancer centers offer treatment protocols for most types of cancer that occur in children and adolescents, as well as the opportunity to participate in clinical trials.

The Arizona Cancer Coalition's Childhood Cancer Work Group is composed of health care providers, philanthropic leaders, community advocates, and, most importantly, families. Together this group has developed goals, objectives, and strategies that emphasize patient-centered care and strong, supportive networks.

**GOAL:** To provide for Arizona's childhood cancer community through education and community involvement.

	Provide at least three (3) opportunities for health care providers to learn more about diagnosis and management of pediatric cancer patients and survivors of childhood
	cancer by June 2024.

Strategic Options		
1.1	Conduct an assessment of existing aids and resources that discuss pediatric cancer diagnosis and management.	
1.2	Collaborate with clinical and community partners to identify the most appropriate evidence-based approaches and communication channels for educating health care providers.	
1.3	Collaborate with primary care practices, clinics, hospitals, and treatment centers to disseminate and evaluate the educational opportunities and any developed materials that accompany them.	

NOTES .

**Identify, adopt and implement** at least **two (2) evidence-based interventions (EBI)** that address **disparities** within the realm of **pediatric cancer** care by June 2024.



Strategic Options					
<ul><li>Conduct an assessment of existing intervention</li><li>are specific to culturally-appropriate pediatric</li><li>care in Arizona.</li></ul>					
2.2	Identify specific subpopulations and interventions that can accompany existing programs and resources.				
2.3	Convene stakeholders to promote, implement and evaluate these culturally-tailored EBIs.				

Objective	Based on the outcomes of a needs assessment, <b>identify and address two (2)</b> key issues for the Adolescent & Young Adult cancer population in Arizona and their families while
(3)*	<b>increasing knowledge of resources and best practices</b> for care of this populations by June 2024.

Objective	Collate and improve access to local and national childhood cancer resources for chil-
	dren, adolescent young adults, siblings, and families through the <b>development</b> of an
(4)	accessible <b>resource website</b> related to childhood cancer by June 2024.

	Strategic Options		
4.1	Assess the quantity and quality of existing childhood cancer resources and identify any gaps.		
4.2	Collaborate with coalition members, community organizations, health care professionals, and advocates to crowd source resources to be included on		
4.3	Collaborate with primary care practices, clinics, hospitals and cancer treatment centers to market and navigate patients to the resource.		

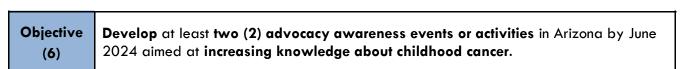


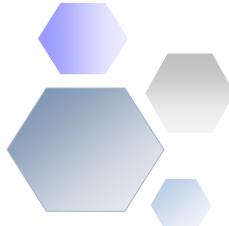
\*Objective and strategies under further review. Updates will be provided in cancer plan's addendum in 2022.

# CHILDHOOD CANCER

	Objective	Develop and implement an advocacy toolkit for parents by June 2024 to increase
		their knowledge and skills related to advocating for their child and empowering them
	(5)	to better advocate for their child pre- and post-cancer treatment.

	Strategic Options			
5.1	Conduct an assessment of existing advocacy resources that focus on pediatric cancer and related research.			
5.2	Convene clinical, community and legislative partners to gather resources to be included in the advocacy tool kit.			
5.3	Identify appropriate channels of communication and dissemination of the childhood cancer advocacy toolkit as well as evaluation tactics.			





Strategic Options				
6.1	Identify opportunities to advocate and partner with organizations that champion childhood cancer prevention, control and treatment.			
6.2	Utilize patient advocates, families, health providers and community members to promote these awareness events and activities.			

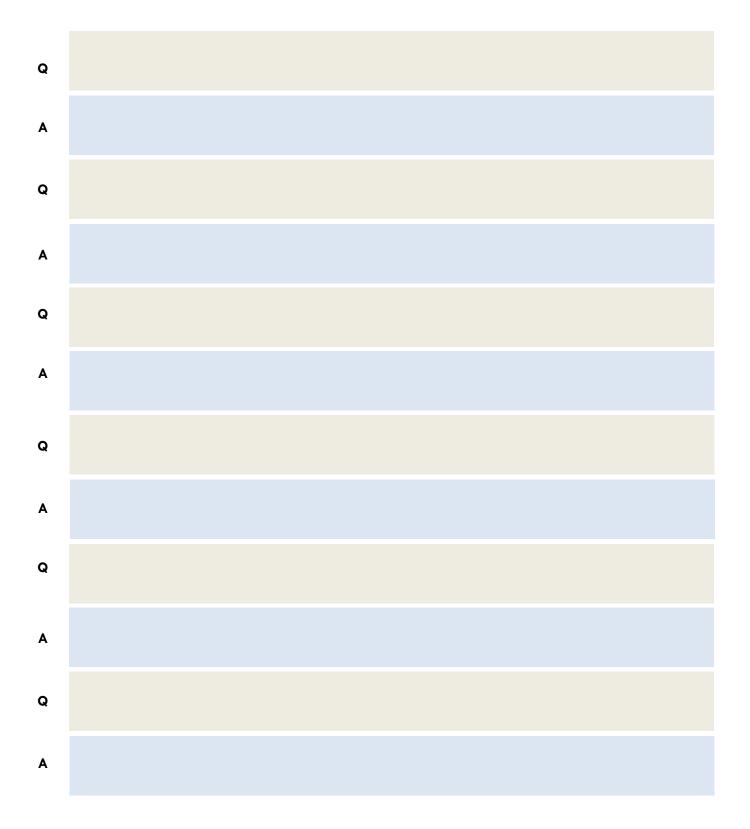
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#### NOTES .

### **QUESTIONS YOU MAY HAVE & ANSWERS YOU MAY NEED**

At this point, you've had a chance to read through all of the work group goals, objectives and strategies. While we hope that we're continuing to provide you with enough explanation, we recognize that you may still have lingering questions. That is why we've provided this space to list questions that you may have. We also encourage you to reach out to our office or visit us online at www.azdhs.gov/cancer for more information.



### Arizona Cancer Control Plan Tracking

The 2020—2024 Arizona Cancer Control Plan is a living document that should be edited and updated on a consistent basis. As the needs and dynamics of our communities change, so should the plans that assist them in the fight against cancer. To provide our readers with a means of tracking our progress, we have provided logs for each objective outlined in this plan. It is the hope of the Arizona Cancer Coalition and its many stakeholders that by the end of 2024 we will have accomplished each of these tasks and moved that much closer to a cancer-free Arizona.

EARLY DETECTION & PREVETION				
		Sta	itus	
Objective	Not Begun	In Progress	Completed	Date
1				
2				
3				
4				
5				
6				

TREATMENT					
	Status				
Objective	Not Begun	In Progress	Completed	Date	
1					
2					
3					

SURVIVORSHIP & QUALITY OF LIFE					
Objective	Status				
Objective	Not Begun	In Progress	Completed	Date	
1					
2					
3					
4					
5					

POLICY				
	Status			
Objective	Not Begun	In Progress	Completed	Date
1				
2				
3				

CHILDHOOD CANCER				
Objective		Sta	itus	
	Not Begun	In Progress	Completed	Date
1				
2				
3				
4				
5				
6				

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# PART IV

# RESOURCES

# HOW THEY ALIGN: THE ARIZONA CANCER CONTROL PLAN AND THE ARIZONA HEALTH IMPROVEMENT PLAN

Arizona Department of Health Services (ADHS) began their accreditation work with the creation of a State Health Assessment. The assessment provided a snapshot of Arizona's health status, issues, and concerns. The county health departments conducted their own county health assessments (CHAs) and this information was integrated into the state's health assessment. The continuation of this process is the creation of health improvement plans at the state and county level. At the state level, the health improvement plan is referred to as the Arizona State Health Improvement Plan (AzHIP); at the county level, the County Health Improvement Plan, or CHIP.

Creation of the AzHIP is led by a steering committee. The steering committee designed tools for gathering and consolidating information from throughout ADHS. Each area of ADHS was asked to address specific topics and summarize an area of focus. The Cancer Work Group has supported the AzHIP over the last four years through constant communication and collaboration on initiatives geared to reduce the disease's burden in Arizona. From the initial develop of the AzHIP to the present, cancer has gone from the leading cause of disease-related death in the state to the second-leading cause.

As ADHS and the counties continue refining and executing their health assessments, the Arizona Cancer Coalition and the ADHS Cancer Prevention and Control Programs working to make sure that the priorities of both plans compliment one another. The Arizona Cancer Control Plan contains objectives to be achieved by the Arizona Cancer Coalition Work Groups and partners over the next five years.

The authors of the AzHIP and Arizona Cancer Control Plan are committed to maintaining alignment through shared goals, objectives and strategies. This alignment will support:

- Data Based Decision Making;
- Prioritized efforts, based upon data, to be the focal point of many;
- Broadened input on priorities from many stakeholders;
- An infrastructure, the work groups, already taking action geared toward reducing the burden of cancer in Arizona; and
- Stakeholders from across the state who are willing to support these actions.

As ADHS and the county health departments embark on developing the next state health improvement plan, the Arizona Comprehensive Cancer Control Program and Arizona Cancer Coalition strive to uphold the dynamic relationship they have with the AzHIP Steering Committee and the communities which they serve.

# **ADHS CANCER PROGRAMS & RESOURCES**

The Arizona Department of Health Services (ADHS) possesses several programs working collaboratively to address the burden of cancer in Arizona. The Bureau of Public Health Statistics; Office of Health Registries, houses the Arizona Cancer Registry at the Arizona Department of Health Services. The Office of Cancer Prevention and Control resides in the Division of Public Health Prevention, Bureau of Chronic Disease and Health Promotion, at ADHS. Together, these programs make up the Arizona Cancer Prevention and Control Team.

#### Arizona Cancer Registry

The Arizona Cancer Registry is a population-based surveillance system that collects, manages and analyzes information on the incidence, survival and mortality of persons having been diagnosed with cancer. The Arizona Cancer Registry began collecting cancer case information in 1981. Initially, reporting by hospitals was voluntary. In 1988, an amendment mandating cancer case reporting was made to Arizona Revised Statute §36-133. Pursuant to the changes in the law, rules detailing how and when cases need to be reported became effective in 1992. The rules require that hospitals, clinics, physicians, dentists, registered nurse practitioners, and doctors of naturopathic medicine report cases to the Registry (Arizona Administrative Code Title 9, Chapter 4).

#### Well Woman HealthCheck Program (WWHP)

The Well Woman HealthCheck Program (WWHP) was established in 1993 as part of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) administered by the Centers for Disease Control and Prevention. This program helps low-income, uninsured, and underinsured women gain access to breast and cervical cancer screening and diagnostic services, including: clinical breast exams, mammograms, pap tests, and pelvic exams. Diagnostic testing such as ultrasounds, biopsies, other tests are also available, if screening results are abnormal. Referrals are made for treatment as necessary. In addition, the WWHP helps verify the eligibility and facilitate the enrollment of uninsured women in Arizona diagnosed with breast or cervical cancer or precancerous cervical lesions into the <u>Breast and Cervical</u> <u>Cancer Treatment Program (BCCTP)</u> provided by the state Medicaid system (AHCCCS).

#### Arizona Comprehensive Cancer Control (AzCCC) Program

The Arizona Comprehensive Cancer Control (AzCCC) Program is also a part of a national program administered by the CDC and executed in all 50 states, 7 U.S. territories and within 8 federally recognized tribal nations. The program works to meet the national priorities of 1) primary prevention, 2) early detection and treatment, 3) survivorship, and 4) health equity. This is accomplished by working across other programs within ADHS and by convening the Arizona Cancer Coalition (ACC). Together these stakeholders develop work plans that focus on each area of the cancer care continuum. Their plans are combined every so often to make up the five-year Arizona Cancer Control Plan.









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