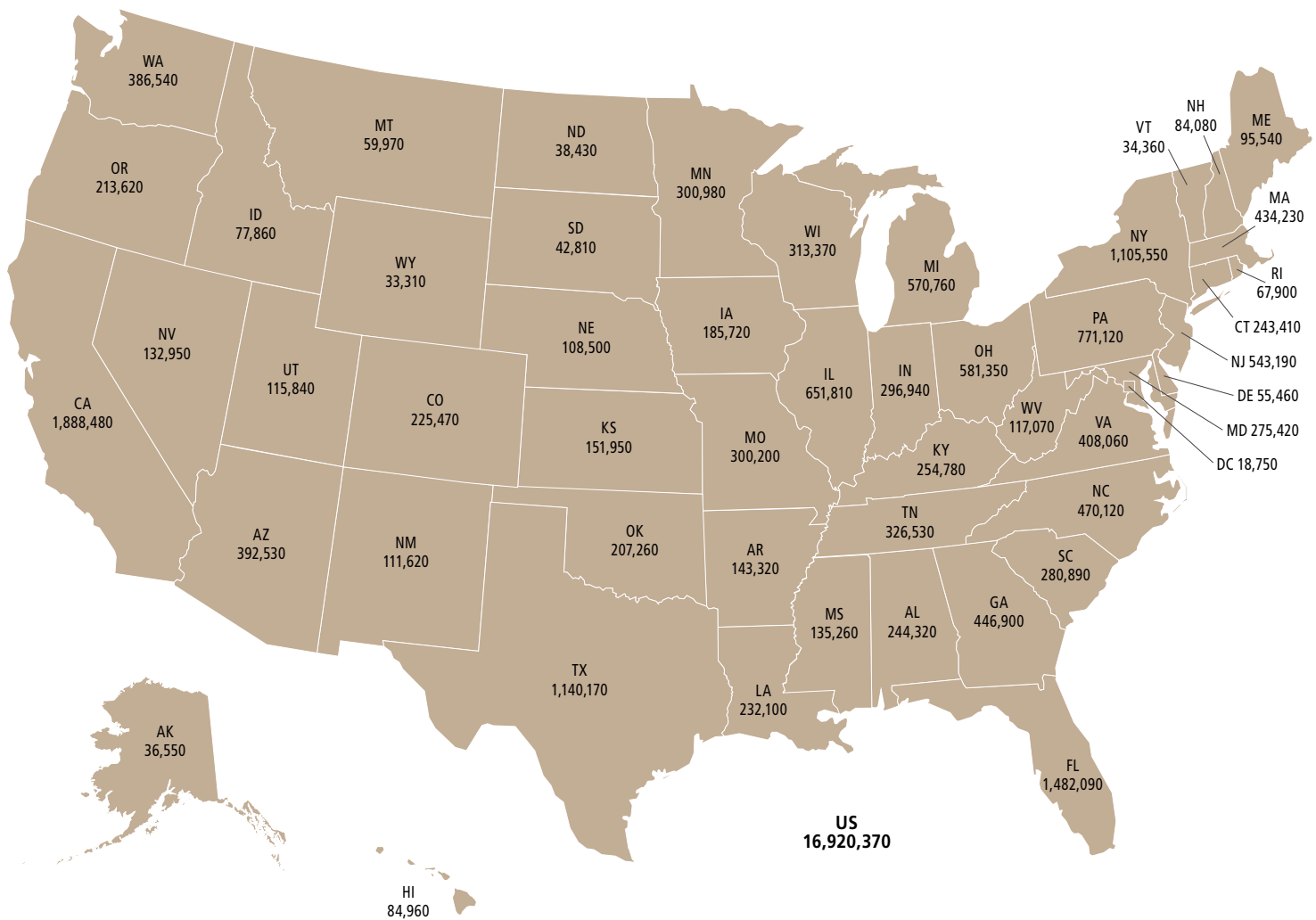


# Cancer Treatment & Survivorship Facts & Figures 2019-2021

Estimated Numbers of Cancer Survivors by State as of January 1, 2019



States estimates do not sum to US total due to rounding.

Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

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*This publication attempts to summarize current scientific information about cancer. Except when specified, it does not represent the official policy of the American Cancer Society.*

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# Introduction

## Who Are Cancer Survivors?

The number of cancer survivors living in the United States continues to increase each year as a result of the growth and aging of the population, as well as increases in survival due to changes in early-detection practices and treatment advances. The survivor population represents a diverse range of experiences with cancer. Information about current treatment patterns and cancer survivorship issues can help the public health community meet the needs of this expanding and heterogeneous population.

Cancer prevalence is defined as the total number of cancer survivors living in a population. In this report, the term “cancer survivor” refers to any person with a history of cancer, from the time of diagnosis through the remainder of their life. However, many people with a history of cancer do not identify with the term “cancer survivor.”<sup>1</sup>

The definition of cancer survivorship has evolved from a focus on three phases (the time from diagnosis to the end of initial treatment, the transition from treatment to extended survival, and long-term survival) to encompass a wide range of experiences and trajectories. For example, some individuals may live cancer free for the remainder of their life after initial treatment, while others may live with cancer as a chronic disease or experience recurrence or a subsequent cancer.

This report summarizes current statistics on cancer prevalence and initial treatment patterns in the United States. Available information on long-term and late effects of cancer and its treatment, recurrence and subsequent cancers, financial hardships, and health behaviors among cancer survivors is also presented.

**Figure 1. Estimated Number of US Cancer Survivors by Site**

	Male		Female	
<b>As of January 1, 2019</b>	Prostate	3,650,030	Breast	3,861,520
	Colon & rectum	776,120	Uterine corpus	807,860
	Melanoma of the skin	684,470	Colon & rectum	768,650
	Urinary bladder	624,490	Thyroid	705,050
	Non-Hodgkin lymphoma	400,070	Melanoma of the skin	672,140
	Kidney & renal pelvis	342,060	Non-Hodgkin lymphoma	357,650
	Testis	287,780	Lung & bronchus	313,140
	Lung & bronchus	258,200	Uterine cervix	283,120
	Leukemia	256,790	Ovary	249,230
	Oral cavity & pharynx	249,330	Kidney & renal pelvis	227,510
	<b>All sites</b>	<b>8,138,790</b>	<b>All sites</b>	<b>8,781,580</b>
	<b>As of January 1, 2030</b>	Prostate	5,017,810	Breast
Colon & rectum		994,210	Uterine corpus	1,023,290
Melanoma of the skin		936,980	Thyroid	989,340
Urinary bladder		832,910	Colon & rectum	965,590
Non-Hodgkin lymphoma		535,870	Melanoma of the skin	888,740
Kidney & renal pelvis		476,910	Non-Hodgkin lymphoma	480,690
Testis		361,690	Lung & bronchus	398,930
Leukemia		352,900	Kidney & renal pelvis	316,620
Lung & bronchus		325,680	Ovary	297,580
Oral cavity & pharynx		315,750	Uterine cervix	288,710
<b>All sites</b>		<b>10,995,610</b>	<b>All sites</b>	<b>11,174,200</b>

Estimates for specific cancers account for the fact that some individuals have a history of multiple different cancer types. See Sources of Statistics, page 36, for more information.

**Source:** Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

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## How Many People Have a History of Cancer?

An estimated 16.9 million individuals with a history of cancer were alive on January 1, 2019, in the United States. This estimate does not include carcinoma in situ (noninvasive cancer) of any site except urinary bladder, nor does it include basal cell or squamous cell skin cancers. By January 1, 2030, it is estimated that the population of cancer survivors will increase to more than 22.1 million due to the growth and aging of the population alone (Figure 1).

Currently, cancers of the prostate, colon and rectum (colorectum), and melanoma of the skin are the three most prevalent among males, whereas cancers of the breast, uterine corpus, and colorectum are most prevalent among females (Figure 1).

The majority of cancer survivors (67%) were diagnosed 5 or more years ago, and 18% were diagnosed 20 or more years ago (Table 1). Nearly two-thirds (64%) of survivors are 65 years of age or older, while only 1 in 10 are younger than 50 years of age (Table 2), with considerable variation by cancer type (Figure 2).

**Table 1. Estimated Number of US Cancer Survivors by Sex and Years Since Diagnosis as of January 1, 2019**

Years since diagnosis	Male and Female			Male			Female		
	Number	Percent	Cummulative Percent	Number	Percent	Cummulative Percent	Number	Percent	Cummulative Percent
0 to <5 years	5,527,420	33%	33%	2,921,800	36%	36%	2,605,620	30%	30%
5 to <10 years	3,802,050	23%	55%	1,957,220	24%	60%	1,844,830	21%	51%
10 to <15 years	2,684,620	16%	71%	1,323,430	16%	76%	1,361,190	16%	66%
15 to <20 years	1,855,780	11%	82%	843,970	10%	87%	1,011,810	12%	78%
20 to <25 years	1,198,320	7%	89%	491,980	6%	93%	706,340	8%	86%
25 to <30 years	773,770	5%	94%	290,450	4%	96%	483,320	6%	91%
30+ years	1,078,430	6%	100%	309,960	4%	100%	768,470	9%	100%

Note: Percentages may not sum to cumulative percentages due to rounding.

Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

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**Table 2. Estimated Number of US Cancer Survivors by Sex and Age at Prevalance as of January 1, 2019**

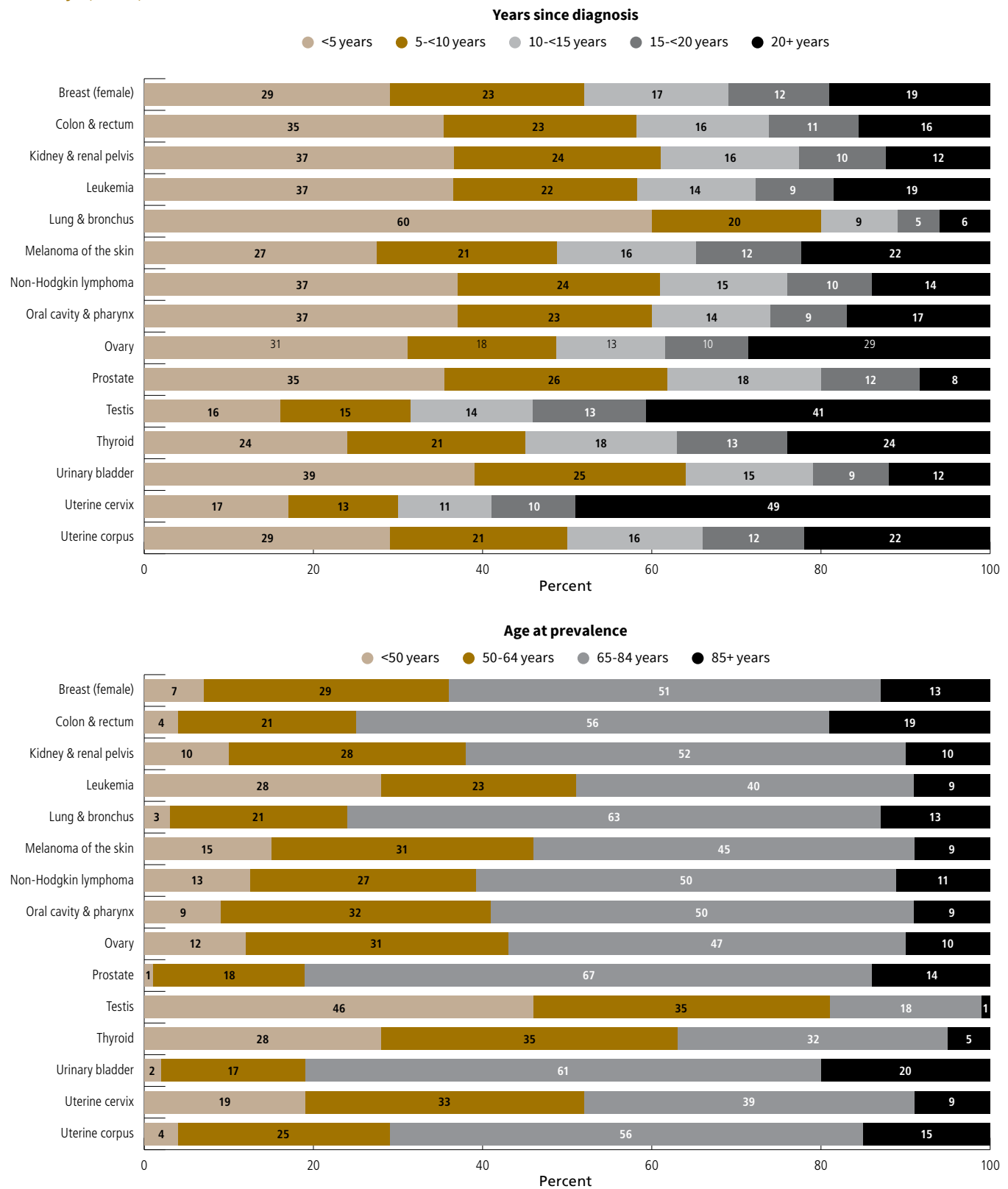
	Male and Female			Male			Female		
	Number	Percent	Cummulative Percent	Number	Percent	Cummulative Percent	Number	Percent	Cummulative Percent
All ages	16,920,370			8,138,790			8,781,580		
0-14	65,850	<1%	<1%	32,300	<1%	<1%	33,550	<1%	<1%
15-19	47,760	<1%	<1%	23,780	<1%	<1%	23,980	<1%	<1%
20-29	194,360	1%	2%	93,540	1%	2%	100,820	1%	2%
30-39	436,300	3%	4%	177,810	2%	4%	258,490	3%	5%
40-49	969,450	6%	10%	351,970	4%	8%	617,490	7%	12%
50-59	2,380,560	14%	24%	964,510	12%	20%	1,416,050	16%	28%
60-69	4,466,900	26%	51%	2,185,200	27%	47%	2,281,700	26%	54%
70-79	4,760,980	28%	79%	2,562,940	32%	79%	2,198,040	25%	79%
80+	3,598,220	21%	100%	1,746,740	22%	100%	1,851,480	21%	100%
0-19	113,610	<1%	<1%	56,090	<1%	<1%	57,520	<1%	<1%
20-64	6,012,430	36%	36%	2,535,730	31%	32%	3,476,700	40%	40%
65+	10,794,330	64%	100%	5,546,970	68%	100%	5,247,360	60%	100%

Note: Percentages may not sum to cumulative percentages due to rounding.

Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

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**Figure 2. Distribution (%) of Survivors for Selected Cancers by Years Since Diagnosis and Age at Prevalence as of January 1, 2019, US**



Percents may not sum to 100% due to rounding.

Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

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## Cancer Staging

Staging describes the extent or spread of cancer at the time of diagnosis and is used to determine treatment options. There are two major staging systems, although some cancers (e.g., lymphoma) have alternative staging. The TNM system is most often used by clinicians and is thus used to describe treatment patterns herein. This system is mainly based on three aspects of cancer: the size of the tumor (T) and/or whether it has grown to involve nearby areas; absence or presence of regional lymph node involvement (N); and absence or presence of distant metastases (M). Once the T, N, and M categories are determined, the tumor is assigned a stage of 0, I, II, III, or IV, with stage 0 referring to a cancer that is limited to the layer of cells in which it originated, stage I being early-stage invasive cancer, and stage IV generally being the most advanced stage (some cancers, such as testicular, do not have a stage IV). For some cancers (e.g., prostate, breast, thyroid), TNM alone does not determine the stage because information such as histologic grade, biomarkers, or even patient age influence stage.

A more simplified system called Summary Stage has historically been used by population-based cancer registries. Cancer that is present only in the original layer of cells where it developed is classified as in situ. If cancer cells have penetrated the original layer of tissue, the cancer is invasive and is categorized as localized (confined to the organ of origin), regional (spread to nearby tissues or lymph nodes in the area of the organ of origin), or distant (spread to distant organs or parts of the body) stage. This staging system is used herein to describe staging for prostate cancer because TNM information for the disease is largely incomplete in population-based cancer registry data.

## Cancer Treatment and Common Side Effects

The goals of treatment are to “cure” the cancer, if possible; prolong survival; and provide the highest possible quality of life during and after treatment. Cancer is considered cured when a patient has no evidence of the disease, including recurrence; thus, it is not possible to know if the cancer is completely eradicated except in hindsight. Some cancers are not curable, often due to

advanced stage. However, for some of these patients, the cancer can be treated as a chronic disease, such as for some metastatic breast cancers.

Cancer treatment can include localized therapies, such as surgery, radiation therapy, cryotherapy, and heat or chemical ablation, and/or systemic therapies (e.g., chemotherapy, hormonal therapy, immune therapy, and targeted therapy) used alone or in combination. Supportive therapies are additional treatments that do not directly treat cancer but are used to reduce side effects and address other patient and family quality of life concerns (e.g., medications to reduce nausea, protect against organ damage from chemotherapy or radiation, or stimulate blood cell production). For some slow-growing cancers, the approach may be to defer immediate treatment and monitor the cancer over time (known as active surveillance). This approach is used for some less aggressive blood cancers and low-risk localized prostate cancer.

Radiation therapy is the use of high-energy beams or particles to kill cancer cells and may be delivered from a source outside the body (as in external beam radiation) or placed internally (e.g., brachytherapy). Systemic therapies are drugs that travel through the bloodstream, potentially affecting all parts of the body, and work using different mechanisms. For example, chemotherapy drugs generally attack cells that grow quickly. Hormonal therapy works by either blocking or decreasing the level of the body’s natural hormones, which sometimes act to promote cancer growth. Targeted therapies work by attacking specific proteins on cancer cells (or nearby cells) that normally help them grow. Immunotherapy stimulates the patient’s immune system to attack the cancer.

The management of physical and psychosocial symptoms and impairments related to cancer and its treatment is also an essential part of cancer care, affecting the delivery and completion of treatment and quality of life. These issues can adversely impact survivors’ ability to return to regular activities and overall financial security following treatment.<sup>2</sup> Cancer rehabilitation can improve pain, functioning, and overall quality of life throughout

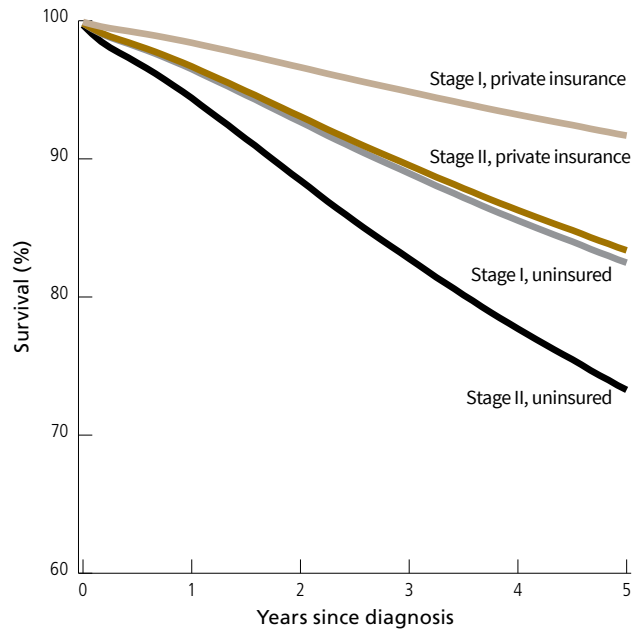
every stage of the treatment process (see Cancer Rehabilitation, page 22).<sup>3</sup> Side effects that arise during treatment improve afterward for many patients but persist for others.<sup>4</sup> Late effects of treatment, such as lymphedema after breast cancer surgery, may arise months or even years later. Both the prevalence and severity of side effects vary from person to person by cancer type, the treatment received, and other factors. The most common side effects of cancer and its treatment are pain, fatigue, and emotional distress,<sup>4-6</sup> although information on late and long-term side effects at the population level is limited. Efforts to facilitate surveillance of long-term and late effects by linking information on health-related quality of life and patient-reported outcomes with population-based cancer registry data are ongoing.<sup>7</sup> General information on side effects of treatment for specific cancer types is described in Selected Cancers, page 6. Additional information on side effects, including patient tools to assist with monitoring effects as they arise, is available on cancer.org (visit [cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html](https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html)).

## Cancer Survival and Access to Care

In this report, survival rates are presented in terms of relative cancer survival, which is the percentage of patients alive at a certain point in time after diagnosis, adjusted for normal life expectancy, and is conventionally presented using 5 years of follow-up. However, 5-year relative survival does not represent the proportion of patients who are cured because some cancer deaths continue to occur more than 5 years after diagnosis. See Sources of Statistics, page 36, for more information about the calculation of survival statistics herein.

Five-year relative cancer survival has improved over the past several decades for most cancer types. Many factors influence survival in addition to cancer type, including age and stage at diagnosis, treatment, insurance status, competing health conditions, and financial resources. Physician and patient factors, including attitudes, beliefs, preferences, and implicit or explicit biases, also influence treatment recommendations and delivery and likely contribute to survival differences.<sup>8</sup> Access to high-quality cancer care increases the likelihood of survival, as well as

**Figure 3. Disparities in Observed Colorectal Cancer Survival by Insurance Status and Stage at Diagnosis, 2010-2014**



Patients were diagnosed during 2010 to 2014 and followed through 2016.

Source: National Cancer Data Base, 2016.

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better patient quality of life. However, optimal cancer care is not universally available, resulting in disparities in stage at diagnosis, treatment, and outcomes for medically underserved populations, such as racial and ethnic minority groups, the uninsured or underinsured, rural populations, and the elderly. Access to quality cancer care can be limited by structural barriers (e.g., inadequate health insurance), complexities of the health care system, and access to transportation or other geographic limitations. Inadequate health insurance is a major barrier to receipt of timely and appropriate care.<sup>9, 10</sup> For example, uninsured patients diagnosed with stage I colorectal cancer have lower survival than stage II colorectal cancer patients with private insurance (Figure 3). Racial/ethnic minorities are both more likely to be underinsured or uninsured and are also more likely to be diagnosed at a later stage for most cancer types (Figure 4). Recent studies have shown that insurance differences account for a substantial proportion of the survival disparity between black and white cancer patients after accounting for age, stage, and other clinical factors.<sup>11, 12</sup>

# Selected Cancers

This section contains information about initial treatment, survival, and common short- and long-term health effects for the most prevalent cancers. It is important to note that certain side effects of cancer treatment, such as pain and fatigue, and cognitive and functional impairments, including sexual dysfunction, are common regardless of cancer type. It is essential that survivors are monitored for such impairments after diagnosis and referred to appropriate rehabilitation services as needed (see Cancer Rehabilitation, page 22).

## Breast (Female)

It is estimated that there were more than 3.8 million women living in the US with a history of invasive breast cancer as of January 1, 2019, and an additional 268,600 women will be newly diagnosed in 2019. The total number of survivors includes more than 150,000 women living with metastatic breast cancer, three-fourths of whom were originally diagnosed with stage I-III disease.<sup>13</sup> Thirty-six percent of female breast cancer survivors are younger than 65 years of age, reflecting the relatively young median age at diagnosis (62 years of age).<sup>14</sup>

### Treatment and survival

About half (49%) of women with stage I or II breast cancer undergo breast-conserving surgery (BCS, i.e., lumpectomy/partial mastectomy, in which only cancerous tissue plus a surrounding layer of normal tissue is removed) followed by radiation therapy, whereas mastectomy (surgical removal of the breast) followed by chemotherapy is most common among women with stage III disease (56%) (Figure 5). Women diagnosed with metastatic disease (stage IV) typically receive radiation and/or chemotherapy without surgery (56%), while 17% receive surgery alone or in combination with other treatments and 26% receive no chemotherapy (including immunotherapy or targeted drugs), radiation, or surgery (some of these patients, however, receive hormonal therapy).

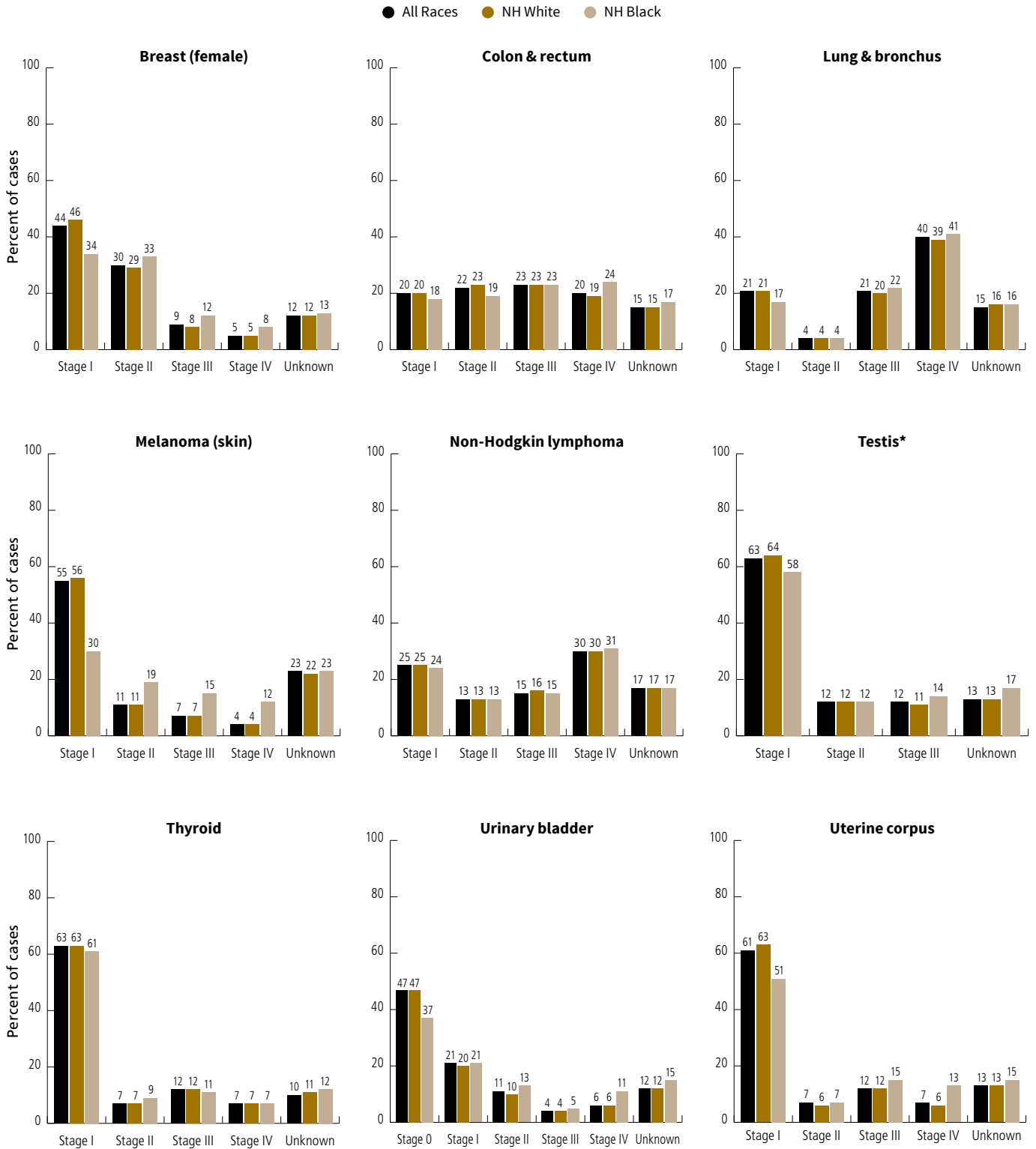
Long-term survival for stage I-II patients treated with BCS followed with radiation to the breast is the same as that for treatment with mastectomy alone.<sup>15,16</sup> However, some patients require mastectomy because of tumor characteristics, such as locally advanced stage, large or multiple tumors, or because they are unable to receive radiation treatment because of preexisting medical conditions, previous receipt of breast radiation, or other obstacles (e.g., limited transportation to treatment).

Despite equivalent survival when combined with radiation, BCS-eligible patients are increasingly electing mastectomy for a variety of reasons, including reluctance to undergo radiation therapy, fear of recurrence, recent advances in reconstructive procedures, and a desire for symmetry.<sup>17-19</sup> Younger women (those under 40 years of age) and patients with larger and/or more aggressive tumors are more likely to undergo unilateral mastectomy (removal of the affected breast) or contralateral prophylactic mastectomy (CPM, the additional removal of the unaffected breast).<sup>20</sup> The percentage of surgically treated women with early-stage disease in one breast who undergo CPM has increased rapidly, from 10% in 2004 to 33% in 2012 among women ages 20-44 years and from 4% to 10% among those 45 years of age and older.<sup>21</sup> Although CPM nearly eliminates the risk of developing a new breast cancer, it does not improve long-term breast cancer survival for the majority of women and is also associated with potential harms.<sup>22-24</sup>

Women who undergo mastectomy may elect to have breast reconstruction, either with a saline or silicone implant, tissue taken from elsewhere in the body, or a combination of the two. Discussions about breast reconstruction should begin prior to mastectomy because the reconstruction process sometimes begins during the mastectomy surgery. A recent large study found that in 2013, 41% of women with breast cancer who received mastectomies underwent immediate reconstructive procedures, more than double the proportion in 2004 (18%).<sup>25</sup> Part of the increase may reflect the parallel rise in women who undergo CPM, who are more likely to receive immediate reconstruction.<sup>19,26</sup>



**Figure 4. Stage Distribution (%) by Race and Cancer Type, 2011-2015**

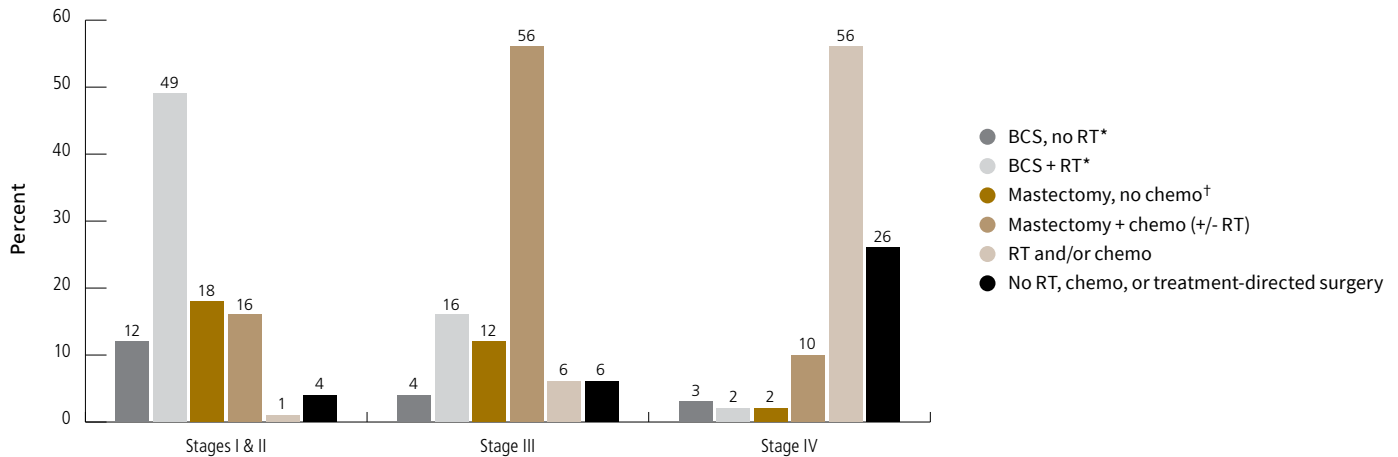


Stage is based on the American Joint Committee on Cancer's Cancer Staging Manual, 6th edition. Prostate is not included because adequate information on prostate specific antigen (PSA) and/or Gleason score, which are necessary for proper staging, was not available for many cases. SEER Summary stage distribution information is available on page 17. \*Testicular cancer does not have a stage IV classification per AJCC, 6th edition.

Source: North American Association of Central Cancer Registries (NAACCR), 2018.

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**Figure 5. Female Breast Cancer Treatment Patterns (%), by Stage, 2016**



BCS = breast conserving surgery, i.e., lumpectomy/partial mastectomy, in which only cancerous tissue plus a surrounding layer of normal tissue is removed; Mastectomy = surgical removal of the entire breast(s); RT = radiation therapy; Chemo = chemotherapy and includes targeted therapy and immunotherapy. \*A small number of these patients receive chemotherapy. †A small number of these patients receive radiation therapy. NOTE: Many patients may have received hormonal therapy in addition to the above treatments. See Sources of Statistics, page 36, for information about hormonal therapy receipt.

**Source:** National Cancer Data Base, 2016.

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The benefit and timing of systemic therapy, which may include chemotherapy, hormonal therapy, or targeted therapy, is dependent on multiple factors, such as the size of the tumor, the number of lymph nodes involved, and the presence of estrogen or progesterone hormone receptors (referred to as ER or PR positive tumors) and/or human epidermal growth factor receptor 2 (HER2) overexpression on the cancer cells. Approximately two-thirds of breast cancers test positive for hormone receptors<sup>27</sup> and can be treated with hormonal therapy. For non-metastatic breast cancer, hormonal therapy may be started before surgery to shrink the cancer (neoadjuvant) but is more often started after other treatments are completed (adjuvant). For premenopausal women, tamoxifen for up to 10 years is standard; however, the combination of ovarian suppression and either tamoxifen or an aromatase inhibitor is recommended for those women with a high risk of recurrence.<sup>28</sup> For postmenopausal women, aromatase inhibitors are the preferred hormonal treatment. The decision to treat with an aromatase inhibitor beyond 5 years is individualized based on patient factors and the expected benefit from the reduction in risk of subsequent breast cancers. For example, patients who have had CPM would be expected to have limited benefit from extending treatment. Other

hormonal therapy drugs and/or targeted drugs (e.g., CDK4/6 inhibitors for hormone receptor-positive, HER2-negative disease)<sup>29</sup> are available for treatment of advanced disease.

The overall 5-year relative survival for breast cancer in women is 90%.<sup>14</sup> Five-year relative survival approaches 100% for women diagnosed with stage I breast cancer and declines to 26% for patients diagnosed with stage IV disease.<sup>30</sup> In addition to stage and age, other factors that influence breast cancer survival include tumor grade, hormone receptor status, and HER2 status. Female breast cancer survival has increased over time due to earlier detection from widespread mammography use and improvements in treatment, particularly for hormone-receptor positive and HER2 positive tumors.<sup>14,31</sup> However, compared to white women, black women remain less likely to be diagnosed at earlier stages (Figure 4) and have lower survival within each stage, with the largest disparity for stage III disease (76% in whites versus 63% in blacks).<sup>30</sup> These racial disparities are complex but are largely explained by socioeconomic disparities that result in less access to high-quality medical care,<sup>11,32</sup> as well as the higher incidence of comorbidities and aggressive tumor characteristics among black women.<sup>11</sup>

## Short- and long-term health effects

Lymphedema of the arm is swelling caused by removal of or damage to underarm lymph nodes during breast cancer surgery or radiation therapy that can develop soon after treatment or years later. It has been estimated that about 20% of women who undergo axillary lymph node dissection and about 6% of women who undergo sentinel lymph node biopsy will develop arm lymphedema.<sup>33</sup> Some evidence suggests that certain exercises, when supervised by a trained professional, and other forms of cancer rehabilitation may reduce the risk and lessen the severity of this condition.<sup>34-35</sup>

Other long-term local effects of surgical and radiation treatment include numbness, tingling, and tightness in the chest wall, arms, or shoulders. Some women have persistent nerve pain in the chest wall, armpit, and/or arm after surgery. Although this type of pain is often referred to as postmastectomy pain syndrome, it can occur after BCS as well. Recent studies suggest that about one-third of women develop persistent pain after breast cancer surgery or radiation therapy,<sup>36</sup> with younger women and those who underwent axillary lymph node dissection having higher risk.<sup>7</sup>

In addition, some breast cancer treatments increase the risk of cognitive impairment and systemic and psychological long-term and late effects. The American Society for Clinical Oncology recently issued guidelines for the prevention and monitoring of cardiovascular problems associated with some breast cancer treatments (e.g., high dose radiation therapy to the chest, HER2 targeted drugs).<sup>38</sup> Reports of sexual dysfunction are common in breast cancer survivors yet often go unaddressed.<sup>39</sup> Younger breast cancer patients may experience impaired fertility,<sup>40</sup> and survivors who undergo premature menopause are at increased risk of osteoporosis.<sup>41</sup> Treatment with aromatase inhibitors, generally reserved for postmenopausal women, can also cause osteoporosis, as well as muscle pain and joint stiffness/pain,<sup>42</sup> while tamoxifen treatment can slightly increase the risk of endometrial cancer (cancer of the lining of the uterus) and blood clots.<sup>43</sup> Hormonal treatments for breast cancer can also cause menopausal symptoms, such as hot flashes, night sweats, and vaginal

dryness, which can lead to pain during intercourse. Negative body image is an important concern in breast cancer patients, affecting an estimated 15% to 30% of long-term survivors, particularly those who receive mastectomy without reconstruction.<sup>44</sup>

For more information about breast cancer, see *Breast Cancer Facts & Figures*, available online at [cancer.org/statistics](https://www.cancer.org/statistics).

## Cancers in Children and Adolescents

It is estimated that there were 65,850 cancer survivors ages 0-14 years (children) and 47,760 survivors ages 15-19 years (adolescents) living in the US as of January 1, 2019, and an additional 11,060 children and 4,990 adolescents will be diagnosed in 2019. Leukemia survivors account for about one-third of all cancer survivors younger than 20 years of age.<sup>14</sup> When combined with adult survivors, there are close to 400,000 survivors of childhood and adolescent cancer, reflecting of the relatively high survival rates for many of these cancers in recent decades.<sup>45</sup>

### Treatment and survival

Pediatric cancers – those that most commonly occur in children – are often treated in specialized centers with a coordinated team of experts, including pediatric oncologists, surgeons, and nurses; social workers; child life specialists; and psychologists. It is usually most appropriate for adolescents diagnosed with pediatric cancers to be treated at pediatric facilities or by pediatric specialists rather than by adult-care specialists, partly because they are more likely to offer the opportunity for participation in clinical trials.<sup>46</sup> Studies have shown that adolescent patients diagnosed with acute lymphocytic leukemia (ALL) have better outcomes on pediatric than adult protocols.<sup>47</sup> However, teen patients with cancers that are more common among adults, such as breast, melanoma, testicular, and thyroid, may be more appropriately treated by adult-care specialists.<sup>48</sup>

For all childhood and adolescent cancers combined, the 5-year relative survival rate increased from 58% during 1975-1977 to 84% during 2008-2014 among children and

from 68% to 85% among adolescents, due to new and improved treatments.<sup>14</sup> However, survival varies considerably depending on cancer type, patient age, and other characteristics. For example, the 5-year relative survival for some of the most common cancers in children is 98% for Hodgkin lymphoma and 91% for ALL but falls to 73% for brain and central nervous system tumors (excluding benign and borderline brain tumors) and 70% for rhabdomyosarcomas and osteosarcomas.

### Short- and long-term health effects

People with a history of childhood or adolescent cancer can experience treatment-related side effects for the remainder of life. Aggressive treatments used for childhood cancers, especially in the 1970s and 1980s, have resulted in a number of late effects, including an increased risk of subsequent cancers. A large follow-up study of pediatric cancer survivors found that almost 10% developed a subsequent cancer (most commonly female breast, thyroid, and bone) over the 30-year period following initial diagnosis.<sup>49</sup> Another study found that 50% of these survivors had developed a severe or life-threatening chronic health condition by 50 years of age.<sup>50</sup> More than half of children exposed to cancer treatments potentially toxic to the heart or lungs (e.g., chest radiation and anthracyclines) develop issues with these organs,<sup>51</sup> and treatments affecting the reproductive organs may cause infertility in both male and female patients. In addition, persistent effects of childhood cancer may result in the failure to achieve social goals or mental health well-being comparable to that among peers without a cancer history.<sup>48</sup>

As a result, it is important that survivors of pediatric cancers are monitored for long-term and late effects. The Children's Oncology Group (COG), a National Cancer Institute-supported clinical trials group that cares for more than 90% of US children and adolescents diagnosed with cancer, has developed long-term follow-up guidelines for managing late effects in survivors of childhood cancer. Visit the COG website at [survivorshipguidelines.org](http://survivorshipguidelines.org) for more information on childhood cancer management.

For detailed information on cancer in children and adolescents, see the special section of *Cancer Facts & Figures 2014*, available online at [cancer.org/statistics](http://cancer.org/statistics).

## Colon and Rectum

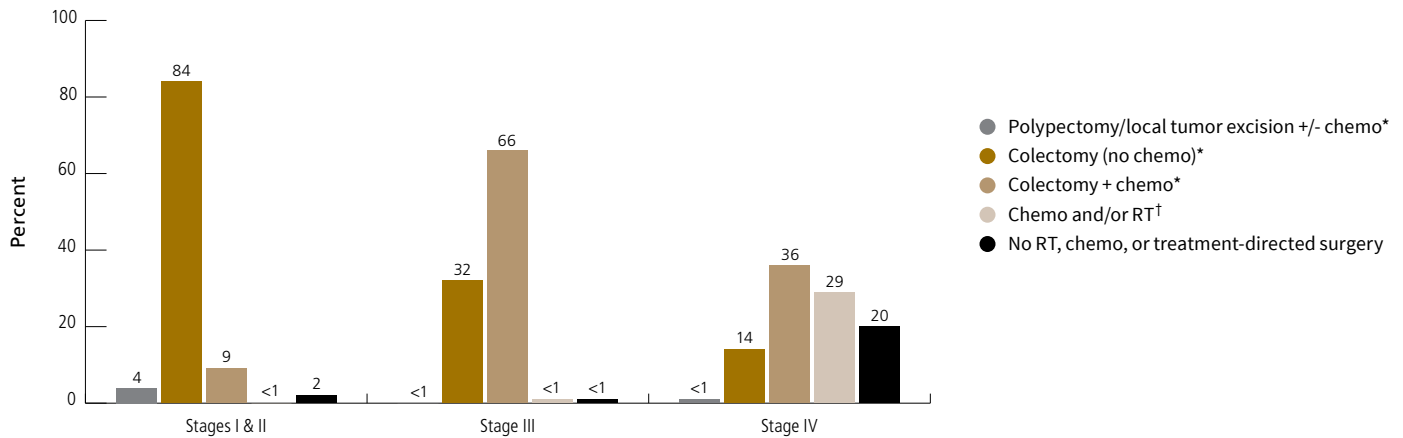
It is estimated that as of January 1, 2019, there were more than 1.5 million men and women living in the US with a previous colorectal cancer diagnosis, and an additional 145,600 cases will be diagnosed in 2019. Patients with rectal cancer tend to be younger at diagnosis than those with colon cancer (median age 63 versus 69, respectively).<sup>14</sup> About three-fourths of colorectal cancer survivors are 65 years of age or older (Figure 2).

### Treatment and survival

The majority of stage I and II colon cancer patients are treated with colectomy (surgical removal of all or part of the colon) without chemotherapy (84%), while those with stage III disease usually receive adjuvant chemotherapy (66%) (Figure 6). For rectal cancer, 61% of stage I patients have a proctectomy (surgical removal of the rectum) or proctocolectomy (removal of the rectum and all or part of the colon), about half of whom also receive radiation and/or chemotherapy (Figure 7). In contrast to colon cancer, stage II and III rectal cancers are often treated with chemotherapy combined with radiation before surgery (neoadjuvant). Surgical treatment is possible for some stage IV colon and rectal cancers with limited spread to other organs (e.g., the liver). Chemotherapy is the most common treatment for metastatic colon or rectal cancer, and a number of targeted drugs are also available. Immunotherapy may be appropriate depending on the tumor's molecular characteristics.<sup>52</sup>

Patients undergoing surgery may need an ostomy, which is the creation of an abdominal opening, or stoma, for elimination of body waste. A stoma created from the large intestine is called a colostomy. In many cases, once the colon or rectum heals, the stoma is closed and the ends of the large intestine reconnected in a procedure called colostomy reversal. Rectal cancer patients require a colostomy more often than colon cancer patients (29% versus 12%, respectively).<sup>53</sup> A permanent colostomy may

**Figure 6. Colon Cancer Treatment Patterns (%), by Stage, 2016**

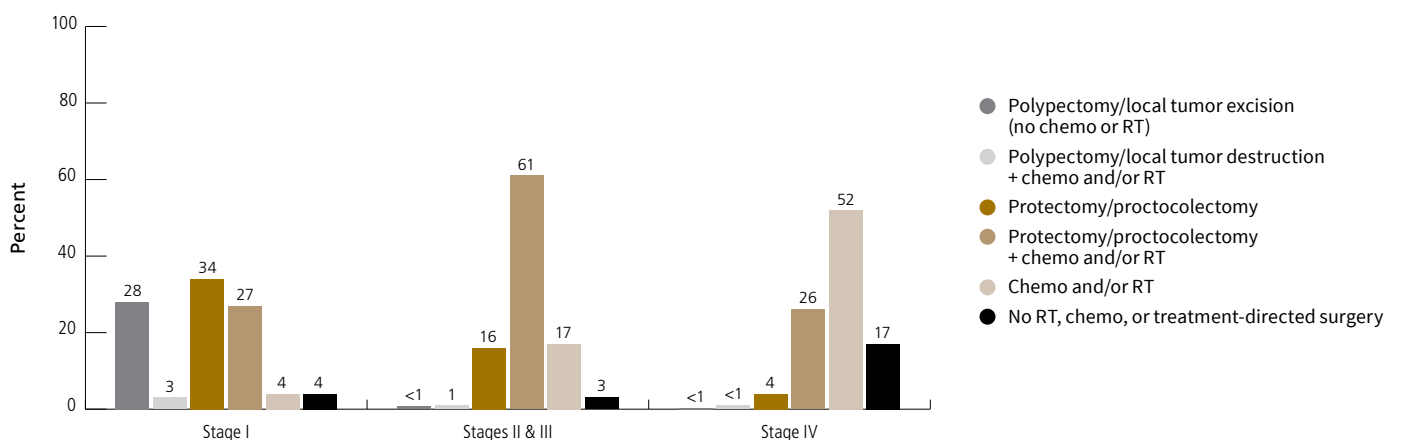


Chemo = chemotherapy and includes targeted therapy and immunotherapy; Colectomy = surgical removal of all or part of the colon; Polypectomy = removal of a polyp; RT = radiation therapy. \*A small number of these patients also receive radiation therapy. †Only a very small proportion of patients received RT alone.

Source: National Cancer Data Base, 2016.

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**Figure 7. Rectal Cancer Treatment Patterns (%), by Stage, 2016**



Chemo = chemotherapy and includes targeted therapy and immunotherapy; Polypectomy = removal of a polyp; Proctectomy = surgical removal of the rectum; Proctocolectomy = removal of the rectum and all or part of the colon; RT = radiation therapy.

Source: National Cancer Data Base, 2016.

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be required if the anus and the sphincter muscle are removed during surgery.

The 5-year survival rate is 91% for stage I colorectal cancer and 82% for stage II;<sup>30</sup> however, only 20% and 22% of patients, respectively, are diagnosed at these stages (Figure 4), in part due to the underuse of screening. Survival declines to 68% for stage III and 12% for stage IV disease. Overall 5-year survival is slightly higher for rectal (67%) versus colon cancer (64%).<sup>14</sup>

## Short- and long-term health effects

Long-term survivors of colorectal cancer report good overall quality of life compared with that of the general population, but higher rates of depression.<sup>54</sup> About half of colorectal cancer survivors experience chronic diarrhea.<sup>55</sup> Bowel dysfunction (including increased stool frequency, incontinence, and perianal irritation) is common among rectal cancer survivors, especially those treated with pelvic radiation.<sup>56,57</sup> Rectal cancer survivors,

particularly those with a colostomy, are more likely than colon cancer survivors to experience bladder dysfunction, sexual dysfunction, and negative body image.<sup>58,59</sup> A trained ostomy therapist can address many of these concerns, as well as issues that arise from colostomy care, such as skin irritation and dietary considerations.<sup>60</sup>

Recurrence is not uncommon among colorectal cancer survivors,<sup>61,62</sup> although the exact percentage is unknown because population-based cancer registries do not collect these data. Colorectal cancer survivors are also at increased risk of additional new cancers (subsequent primary cancers) of the colon and rectum, as well as other cancer sites, especially those within the digestive system.<sup>63</sup>

See *Colorectal Cancer Facts & Figures*, available online at [cancer.org/statistics](https://www.cancer.org/statistics), for more information about colorectal cancer.

## Leukemia and Lymphoma

It is estimated that as of January 1, 2019, there were 451,700 people living with a history of leukemia in the US, and an additional 60,140 people will be diagnosed in 2019. Leukemias are classified into four main groups according to cancer cell type and rate of growth: acute lymphocytic leukemia (ALL), chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL; also referred to herein simply as CLL), acute myeloid leukemia (AML), and chronic myeloid leukemia (CML). In this report, CLL is included among leukemias for the purpose of reporting trends, although it is now recognized as a type of lymphoma.

Although leukemia is the most common cancer in children and adolescents combined, the vast majority (92%) of leukemia patients are diagnosed at 20 years of age and older.<sup>64</sup> AML and CLL are the most common types of leukemia diagnosed in adults, whereas ALL accounts for nearly 80% of leukemias in children and about half of those in adolescents. The median age at diagnosis is 15 for ALL, 65 for CML, 69 for AML, and 70 for CLL.<sup>14</sup>

Lymphomas are cancers that begin in cells of the immune system called lymphocytes. There are two major types of lymphomas: Hodgkin lymphoma (HL) and

non-Hodgkin lymphoma (NHL). NHL can be further divided into indolent and aggressive categories, each of which includes many subtypes that progress and respond differently to treatment. It is estimated that as of January 1, 2019, there were 234,890 HL survivors and 757,710 NHL survivors, and that 8,110 and 74,200 new cases of HL and NHL, respectively, will be diagnosed in 2019. HL is one of the most common childhood and adolescent cancers; as a result, the median age at diagnosis for Hodgkin lymphoma (39 years) is substantially younger than that for NHL (67 years of age).<sup>14</sup>

## Treatment and survival

**AML.** Acute myeloid leukemia (also called acute myelogenous leukemia) arises from blood-forming cells, progresses quickly, and is rapidly fatal in the absence of treatment. The standard treatment for AML is two phases of chemotherapy. The first phase, called induction, is designed to clear all evidence of leukemia cells from the blood and bone marrow, putting the disease into complete remission. The goal of the second phase, called consolidation, is to kill any remaining leukemia cells that cannot be seen and would cause relapse if left untreated. Many older adults (among whom the disease is most common) are not able to tolerate the most aggressive and effective regimens.<sup>65</sup> Appropriate treatment is influenced by the patient's age and health, as well as the molecular characteristics of the cancer. Some patients undergo allogeneic stem cell transplantation (in which the transplanted cells come from a donor whose tissue type closely matches the patient's) after receiving chemotherapy, alone or with radiation, as part of a conditioning regimen. A number of targeted drugs are also now available. Additional information on the treatment of AML, as well as the subtype acute promyelocytic leukemia, is available from [cancer.org \(cancer.org/cancer/acute-myeloid-leukemia/treating.html\)](https://www.cancer.org/cancer/acute-myeloid-leukemia/treating.html).

Approximately 60% to 85% of adults 60 years of age and younger with AML can expect to attain complete remission following the first phase of treatment, and 35% to 40% of patients in this age group will be cured.<sup>65,66</sup> In contrast, 40% to 60% of patients older than 60 years of age will achieve complete remission, and only 5% to 15% will be cured. About 4% of AML cases occur in children

and adolescents (ages 0-19 years),<sup>64</sup> for whom the prognosis is substantially better than among adults. The 5-year relative survival is 67% for children and adolescents, but declines to 54%, 32%, and 7% for patients ages 20-49, 50-64 years, and ages 65 years and older, respectively.<sup>30</sup>

**CML.** Chronic myeloid leukemia (also called chronic myelogenous leukemia) is a type of cancer that starts in the blood-forming cells of the bone marrow and invades the blood. Once suspected, CML is usually easily diagnosed because the involved cells contain the BCR-ABL gene, typically found within an abnormal chromosome known as the Philadelphia chromosome. There are three phases of CML: chronic, accelerated, and blast. The chronic phase is the least aggressive and is characterized by no or mild symptoms; the accelerated phase has noticeable symptoms, such as fever, poor appetite, and fatigue; and the blast phase is the most aggressive and has more severe symptoms and may rapidly lead to death.

The standard treatments for CML are targeted drugs (e.g., imatinib), which are very effective at inducing remission and decreasing progression to the accelerated phase. In the past, it was thought that these drugs had to be taken indefinitely to keep the disease in check; however, recent studies have found they can be safely discontinued in a subset of patients.<sup>67</sup> If the leukemia becomes resistant to one tyrosine kinase inhibitor, another may be tried. For cancers that are resistant to tyrosine kinase inhibitors, chemotherapy or stem cell transplantation may be used. In part due to the discovery of these targeted therapies, the 5-year survival rate for CML has more than doubled over the past 25 years, from 31% for those diagnosed during 1990-1992 to 69% for those diagnosed during 2008-2014.<sup>14</sup>

**ALL.** Acute lymphocytic leukemia (also called acute lymphoblastic leukemia) is a disease in which too many immature lymphocytes (a type of white blood cell) are produced in the bone marrow. More than half (54%) of all ALL cases are diagnosed in patients younger than 20 years of age.<sup>64</sup> The disease typically progresses rapidly without treatment, which is generally delivered in three phases and consists of 4-6 weeks of induction chemotherapy (given to induce remission and often administered in the hospital), followed by several months of consolidation (or

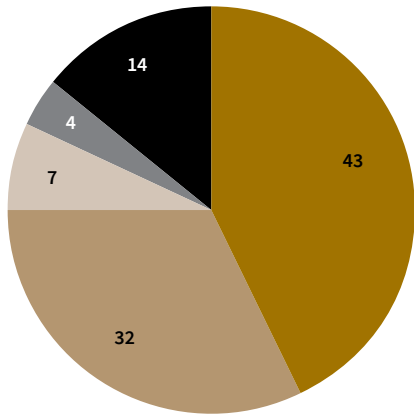
intensification) therapy, and 2-3 years of maintenance chemotherapy.<sup>68</sup> Some ALL patients have a chromosomal abnormality similar to that in CML and benefit from the addition of a tyrosine kinase inhibitor. More than 95% of children and 78%-92% of adults with ALL attain remission. Stem cell transplantation is recommended for some patients whose leukemia has high-risk characteristics at diagnosis and for those who relapse after remission. It may also be used if the leukemia does not go into remission after successive courses of induction chemotherapy. Chimeric antigen receptor (CAR) T-cell therapy, which genetically modifies the patient's immune system to fight the cancer, is also an option for patients with a specific subtype of ALL who have relapsed or not responded to other treatments.<sup>69</sup>

Survival rates for patients with ALL have increased rapidly over the past 3 decades, particularly among children.<sup>14</sup> In addition, the black-white 5-year survival disparity for children with ALL has declined from a 16 percentage point difference during 1980-1982 (55% versus 71%, respectively) to an 8 percentage point difference during 2008-2014 (85% versus 93%, respectively).<sup>66</sup> Survival dramatically declines with increasing age; the current 5-year survival rate is 89% for ages 0 to 19 years, 47% for ages 20 to 49 years, 28% for ages 50 to 64 years, and 17% for those 65 years of age and older.<sup>30</sup>

**CLL/SLL.** Chronic lymphocytic leukemia/small lymphocytic lymphoma is characterized by the overabundance of mature lymphocytes in the blood and bone marrow. It usually progresses slowly and is most commonly diagnosed in older adults. Treatment is not likely to cure and is generally reserved for symptomatic patients or those who have low counts of normal (non-leukemic) blood cells or other complications. For patients with early disease, active surveillance (carefully monitoring over time for disease progression) is a common approach. For patients with more advanced disease, available treatments, which include chemotherapy, immunotherapy, and/or targeted therapies, can delay the progression of disease, but may not extend survival.<sup>70-72</sup> CAR-T cell immunotherapy has also been used in patients with disease that has relapsed or not responded to other treatments.<sup>69</sup> The overall 5-year relative survival for CLL is 84%, although

**Figure 8. Diffuse Large B-Cell Treatment Patterns (%), 2012-2016**

- Chemo + immunotherapy (+/- RT)
- Chemo (no RT or immunotherapy)
- Chemo + RT (no immunotherapy)
- Immunotherapy and/or RT
- No RT, chemo, or immunotherapy



Chemo = chemotherapy and includes targeted therapy; RT = radiation therapy.  
**Source:** National Cancer Data Base, 2016.

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there is a large variation among individual patients, ranging from several months to normal life expectancy.<sup>30</sup>

**HL.** Hodgkin lymphoma is a cancer of the lymph nodes that often starts in the neck, chest, or abdomen. It can be diagnosed at any age, but is most common in early adulthood (about one-third of cases are diagnosed between ages 20 and 34 years). There are two major types of HL. Classical HL is the most common and is distinguishable by the presence of Reed Sternberg cells. Nodular lymphocyte-predominant HL (NLPHL) is rare, comprising only about 5% of cases, and is a more slow-growing disease with a generally favorable prognosis.<sup>73</sup>

Classical HL is usually treated with multi-agent chemotherapy, sometimes in combination with radiation therapy, although the use of radiotherapy is declining.<sup>74</sup> If initial treatment is not effective, a different chemotherapy regimen may be tried, sometimes followed by autologous (“patient’s own”) stem cell transplantation. Other treatment options include radiation or the targeted drug brentuximab vedotin. For patients with NLPHL, radiation therapy alone may be appropriate for early-stage disease.<sup>73</sup> For those with later-stage disease, chemotherapy plus

radiation, as well as the monoclonal antibody rituximab, may be recommended. Five-year survival for all HL combined is 86%, and is higher for NLPHL than for classical HL – 93% versus 83%, respectively.<sup>30</sup>

**NHL.** There are multiple types of non-Hodgkin lymphoma, with the most common types being diffuse large B-cell lymphoma (DLBCL), representing about 4 in 10 cases, and follicular lymphoma, representing 2 in 10 cases.<sup>64</sup> Although DLBCL grows quickly, most patients with localized disease and about 50% with advanced disease are cured with treatment.<sup>75,76</sup> In contrast to most cancers, initial treatment is generally similar across stage, although radiation therapy alone is typically used only in certain cases of early-stage disease.<sup>77</sup> Most DLBCL patients receive chemotherapy (82%), either with (43%) or without (39%) immunotherapy (such as rituximab) (Figure 8).<sup>78</sup> About 14% receive no initial treatment, although the percentage is higher for stage I versus stage IV (19% versus 14%, respectively) disease.<sup>74</sup> Follicular lymphomas tend to grow slowly and often do not require treatment until symptoms develop, but are generally not curable.<sup>79</sup> Some cases of follicular lymphoma transform into DLBCL. If NHL persists or recurs after standard treatment, stem cell transplantation or CAR T-cell therapy may be an option. Five-year survival is 88% for follicular lymphoma and 63% for DLBCL.<sup>30</sup>

### Short- and long-term health effects

Some survivors, such as those who received stem cell transplant, have recurrent infections and low blood cell counts that may require blood transfusions. In addition, allogeneic (i.e., donor cells) transplantation for acute leukemias may lead to chronic graft-versus-host disease, which can cause skin changes, dry mucous membranes (eyes, mouth, vagina), joint pain, weight loss, shortness of breath, and fatigue.<sup>80</sup>

Leukemia treatment regimens that involve anthracyclines can have heart-damaging effects. Chest radiation for Hodgkin lymphoma also increases the risk for various heart complications (e.g., valvular heart disease and coronary artery disease), as well as breast cancer among women treated during childhood or adolescence.<sup>81,82</sup> Certain chemotherapy drugs, as well as high-dose



chemotherapy used with stem cell transplant, can lead to infertility. In the past, most children with ALL received cranial radiation therapy, which is associated with long-term cognitive deficits.<sup>83</sup> This treatment is used less frequently and in lower dosages today.

## Lung and Bronchus

It is estimated that there were 517,350 men and women living in the US with a history of lung cancer as of January 1, 2019, and an additional 228,150 cases will be diagnosed in 2019. The median age at diagnosis for lung cancer is 70.<sup>14</sup>

### Treatment and survival

Lung cancer is classified as small cell (13% of cases) or non-small cell (83%) for the purposes of treatment (3% of cases are unclassified).<sup>64</sup> Depending on type and stage of cancer, treatment may include surgery, radiation therapy, chemotherapy, targeted therapies, and/or immunotherapy.

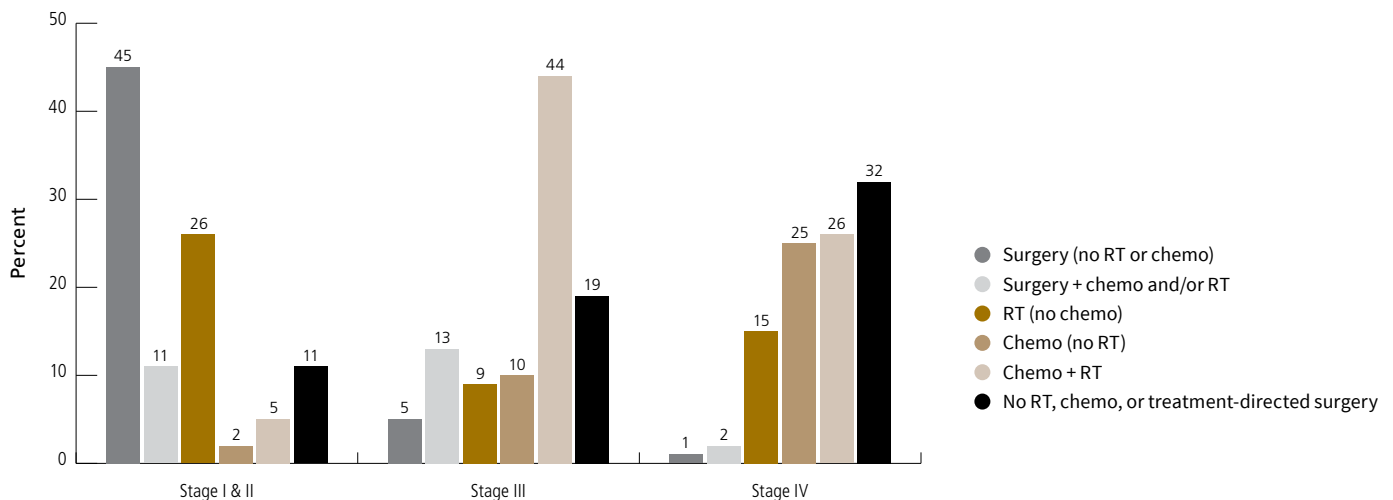
Because small cell lung cancer (SCLC) is rarely truly localized at diagnosis, surgical resection plays little role in treatment. The main treatment for SCLC is chemotherapy.<sup>74</sup> In addition, some patients also receive radiation to the chest, which may be given concurrently with chemotherapy.

Some patients receive prophylactic cranial radiation therapy to help prevent development of brain metastases. More recently, the addition of an immune checkpoint inhibitor to chemotherapy has been shown to improve survival in advanced SCLC.<sup>84</sup>

The majority (56%) of stage I and II NSCLC patients undergo surgery, which usually involves partial (wedge resection) or total (lobectomy) removal of the affected lobe, or partial removal of the affected airway (sleeve resection). (Figure 9). In contrast, only 18% of patients with stage III NSCLC undergo surgery while most (63%) are treated with chemotherapy and/or radiation. Only a very small proportion of all NSCLC patients undergo pneumonectomy (removal of the entire lung), with or without chemotherapy and/or radiation.<sup>74</sup> There are a number of targeted and immunotherapy drugs available to treat advanced NSCLC, but some are only useful in treating cancers with certain genetic mutations. In 2016, about 12% of newly diagnosed stage IV NSCLC patients received immunotherapy.<sup>74</sup>

The 5-year relative survival for lung cancer is 19%.<sup>14</sup> Because symptoms usually do not appear until the disease has spread to other parts of the body, only about 1 in 5 lung cancer patients are diagnosed with stage I disease (Figure 4), for which 5-year survival is 57%.<sup>30</sup> Five-year

**Figure 9. Non-Small Cell Lung Cancer Treatment Patterns (%), by Stage, 2016**



Chemo = chemotherapy, and includes targeted therapy; RT = radiation therapy.

Source: National Cancer Data Base, 2016.

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survival for SCLC (6%) is lower than that for NSCLC (23%) for all stages combined as well for each stage.<sup>14</sup>

### Short- and long-term health effects

Many lung cancer survivors have impaired lung function (especially if they have had surgery and/or had preexisting lung problems due to smoking) and may require long-term supplemental oxygen.<sup>85</sup> In some cases respiratory therapy and medications can improve fitness and allow these survivors to resume normal daily activities. Lung cancer survivors who are current or former smokers are at increased risk for subsequent lung cancers and other smoking-related cancers, especially head and neck or urinary tract cancers. Survivors may feel stigmatized because of the social perception that lung cancer is a self-inflicted disease, which can be particularly difficult for those who never smoked.<sup>86</sup>

## Melanoma of the Skin

It is estimated that there were more than 1.3 million melanoma survivors living in the US as of January 1, 2019, and an additional 96,480 people will be diagnosed in 2019. Women tend to be diagnosed at a younger age than men (60 versus 66 years of age, respectively), reflecting differences by sex and age in occupational and recreational exposure to ultraviolet radiation, as well as frequency of health care interactions. Nearly half of all melanoma survivors (47%) are younger than age 65 (Figure 2).

### Treatment and survival

Surgery to remove the tumor and surrounding tissue is the primary treatment for nonmetastatic melanoma. Patients with stage III melanoma usually also have nearby lymph nodes removed and may be offered immunotherapy after surgery or, if their melanoma contains a BRAF V600 mutation (about half of all skin melanomas), a combination of targeted drugs. Treatment for patients with stage IV melanoma has changed in recent years and typically includes these new immunotherapy and targeted drugs.<sup>87</sup> Several targeted drugs for metastatic melanoma with BRAF/MEK mutations have been shown to improve survival.<sup>88,89</sup> Among patients with metastatic disease who

receive either chemotherapy or immunotherapy, 39% also receive radiation therapy.<sup>74</sup>

The 5-year relative survival rate for melanoma is 92%.<sup>14</sup> More than half (55%) of melanomas are diagnosed at stage I (Figure 4), for which the 5-year relative survival approaches 100%.<sup>30</sup> However, for patients diagnosed with stage IV disease, 5-year survival declines to 19%.

### Short- and long-term health effects

Depending on the size and location of the melanoma, removal can be disfiguring. Patients with several lymph nodes removed during surgery may develop lymphedema. Immunotherapy drugs used to treat melanoma can cause a number of side effects, including inflammation of the lungs, colon, or kidneys, and endocrine disorders (e.g., hypothyroidism and adrenal insufficiency). In addition, men and women who are survivors of melanoma are nearly 13 and 16 times, respectively, more likely than the general population to develop additional melanomas due to skin type and other genetic risk factors and/or overexposure to ultraviolet radiation.<sup>90</sup> Thus, it is important for survivors to monitor their skin and limit sun exposure.

## Prostate

It is estimated that there were more than 3.6 million men with a history of prostate cancer living in the US as of January 1, 2019, and an additional 174,650 men will be diagnosed in 2019. The vast majority (81%) of prostate cancer survivors are 65 years of age or older (Figure 2). The median age at diagnosis is 66 years.<sup>14</sup>

### Treatment and survival

Treatment options vary depending on stage of the cancer, as well as patient characteristics such as age, other medical conditions, and personal preferences. High-quality, national data on prostate cancer treatment patterns are limited, particularly for hormonal (referred to as androgen deprivation therapy, or ADT) and radiation therapies. Active surveillance rather than immediate treatment is a commonly recommended approach for low-risk, localized cancer.<sup>91-93</sup> In a recent

analysis of cancer registry data, active surveillance for low-risk disease increased from 15% to 42% from 2010 to 2015 among men of all ages combined, while radical prostatectomy (removal of the prostate) declined from 47% to 31%.<sup>94</sup> Previous studies have suggested that the increase in active surveillance is most pronounced among men 75 years of age and older.<sup>95</sup>

Higher-risk disease may be treated with radical prostatectomy, radiation therapy, ADT, or a combination thereof. Advanced prostate cancer may be treated with ADT, chemotherapy, radiation therapy, and/or other treatments. Cancers that have metastasized to or are likely to spread to the bone may be treated with bone-directed therapy to prevent fractures and slow cancer spread. ADT is generally the first treatment used for advanced disease and can often control the cancer for long periods, also helping to relieve pain and other symptoms. For men with advanced cancers that stop responding to traditional ADT, newer drugs that block or lower testosterone or lower testosterone further may be effective.<sup>96-99</sup>

Over the past 35 years, the 5-year relative survival rate for all stages combined has increased from 68% to 99%.<sup>14</sup> However, it is unknown how much of the increase is due to detection of indolent disease, which would never cause harm, via screening with the prostate specific antigen test. Most (90%) prostate cancers are diagnosed in the local or regional stages, for which the 5-year relative survival rate approaches 100%. (Summary stage is presented because TNM staging information is incomplete for a large proportion of prostate cancer cases in cancer registry data. See Cancer Staging, [page 4](#)).

### Short- and long-term health effects

Although survival rates are favorable for patients with early-stage disease treated with surgery or radiotherapy (with or without ADT), both are associated with substantial risk of physical impairment (sexual, urinary, and bowel).<sup>100, 101</sup> Many prostate cancer survivors who have been treated with surgery or radiation experience incontinence, erectile dysfunction, and/or bowel complications, which may be permanent.<sup>102</sup> Sexual counseling in this population can be helpful in restoring comfort with intimacy.<sup>39</sup> Patients receiving hormonal

treatment may experience loss of libido, hot flashes, night sweats, irritability, and mild breast development. Hormonal therapy also increases the risk of anemia, osteoporosis, and metabolic syndrome, and may increase the risk of cardiovascular disease and depression.<sup>103-105</sup>

## Testis

It is estimated that there were 287,780 testicular cancer survivors in the US as of January 1, 2019, and an additional 9,560 men will be diagnosed in 2019. Testicular germ cell tumors (TGCTs) account for more than 97% of testicular cancers.<sup>64</sup> These tumors arise from cells that normally develop into sperm cells. The median age at diagnosis for testicular cancer is 33,<sup>14</sup> much younger than most other cancers.

TGCTs are categorized based on cell type as seminomas (55%), nonseminomas (13%), or mixed (28%).<sup>64</sup>

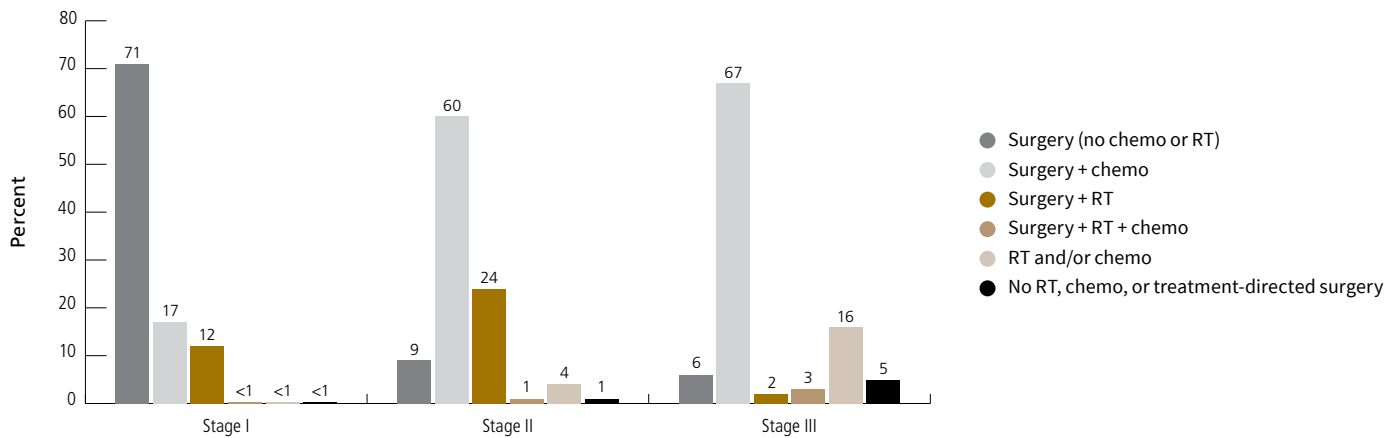
Nonseminomas generally occur among younger men (in their late teens to early 40s) and, along with mixed tumors, tend to be more aggressive. Seminomas are slow-growing and are most often diagnosed in men in their late 30s to early 50s.

### Treatment and survival

Treatment of almost all TGCTs begins with surgery to remove the testicle in which the tumor developed. Most (71%) stage I seminomas are treated with surgery without chemotherapy or radiation, whereas most stage II patients receive surgery followed by chemotherapy (60%), radiation (24%), or both (1%) ([Figure 10](#)). Over the past decade, postsurgery active surveillance has become an increasingly preferred management option for patients with stage I seminomas,<sup>106</sup> and long-term study results support this treatment strategy.<sup>107</sup> Stage III seminomas are usually treated with surgery followed by chemotherapy alone (67%) ([Figure 10](#)).

Although mixed tumors include both cell types, treatment is similar to nonseminomas due to their shared higher risk of progression. Treatment for men with nonseminomas may involve retroperitoneal lymph node dissection (RPLND), which may be recommended after surgery in high-risk cases to reduce the likelihood of

**Figure 10. Treatment Patterns (%) for Seminomatous Testicular Germ Cell Tumors, 2012-2016**

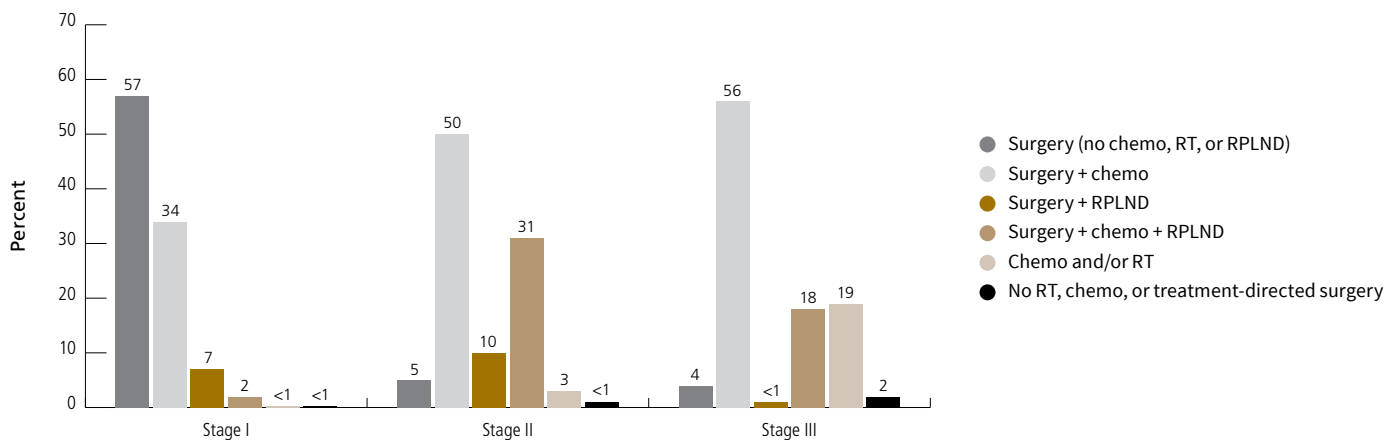


Chemo = chemotherapy, and includes some targeted therapies; RT= radiation therapy.

Source: National Cancer Data Base, 2016.

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**Figure 11. Treatment Patterns (%) for Nonseminomatous Testicular Germ Cell Tumors,\* 2012-2016**



Chemo = chemotherapy, and includes targeted therapy and immunotherapy drugs; RPLND = retroperitoneal lymph node dissection. \*Excluding mixed germ cell tumors.

Source: National Cancer Data Base, 2016.

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recurrence. For men with stage I nonseminomas, more than half (57%) are treated with surgery alone, whereas the majority of stage II patients receive additional treatment after surgery, including chemotherapy (50%); RPLND (10%); or both (31%) (Figure 11). Men with metastatic nonseminomas are usually treated with chemotherapy after surgery, with or without RPLND.

Testicular cancer survival has increased substantially since the mid-1970s, largely due to the success of

chemotherapy regimens for advanced disease. The 5-year relative survival for all testicular cancers combined is 99%.<sup>14</sup> However, survival is lower for nonseminomas (90%) than for mixed TGCTs (94%) and seminomas (99%), regardless of age.<sup>30</sup> Most testicular cancers (63%) are diagnosed at stage I because of a lump on the testicle (Figure 4); 5-year relative survival for this stage approaches 100%.<sup>30</sup> Even cancers diagnosed at stage III may be successfully treated, with a 5-year relative survival of 74%.

## Short- and long-term health effects

Although most men with one healthy testicle produce sufficient male hormones and sperm to continue sexual relations and father children, consultation about fertility risks and sperm banking is recommended prior to treatment if fertility is not already impaired.<sup>40</sup> When cancer occurs in both testicles, lifelong hormone replacement is required. Men treated with chemotherapy are also at increased risk of coronary artery disease as they age and should be particularly mindful of additional risk factors such as high cholesterol, high blood pressure, obesity, and smoking.

## Thyroid

It is estimated that there were 900,590 people (195,540 men and 705,050 women) living with a past diagnosis of thyroid cancer in the US as of January 1, 2019, and an additional 52,070 cases will be diagnosed in 2019. Thyroid cancer commonly occurs at a younger age than most other adult cancers, with a median age at diagnosis of 55 for males and 50 for females.<sup>14</sup> Incidence rates are 3 times higher in women than in men.

### Treatment and survival

Most thyroid cancers are either papillary or follicular carcinomas, both of which are highly curable. About 3% of thyroid cancers are either medullary or anaplastic carcinoma,<sup>64</sup> which tend to be more difficult to treat because they do not respond to radioactive iodine treatment.<sup>108</sup> These types of thyroid cancer also typically grow more quickly and have often metastasized by the time of diagnosis.

The first choice of treatment in nearly all cases is surgery, with patients receiving either total (81%) or partial (15%) thyroidectomy (removal of the thyroid gland).<sup>74</sup> More than half of surgically treated patients with well-differentiated (papillary or follicular) thyroid cancer receive radioactive iodine (I-131) after surgery to destroy any remaining thyroid tissue.<sup>109</sup> If the thyroid has been removed completely, thyroid hormone replacement therapy is required to maintain normal metabolism, and is often given in doses high enough to keep the body from

making thyroid-stimulating hormone to decrease the likelihood of cancer recurrence.

Total thyroidectomy is the main treatment for patients with medullary carcinoma of the thyroid, as I-131 is not absorbed by the cancer cells. External beam radiation therapy may be offered after surgery for cancers with a high risk of local or regional recurrence.<sup>110</sup> For medullary carcinomas that cannot be treated with surgery, targeted drugs or chemotherapy may be offered. Anaplastic thyroid cancers are often widespread at the time of diagnosis, making surgery difficult or impossible. Radiation therapy and/or chemotherapy may be used to treat these cancers, as well as targeted drugs for cancers with BRAF mutations, but response rates are generally poor.

The 5-year relative survival rate for thyroid cancer is 98% overall,<sup>14</sup> 90% for medullary carcinoma, and 7% for anaplastic carcinoma.<sup>30</sup> Five-year survival for stages I, II, and III disease approaches 100%, but is 71% for those diagnosed with stage IV tumors.

## Short- and long-term health effects

Thyroid cancer surgery can damage nerves to the larynx and lead to voice changes.<sup>111</sup> In addition, patients requiring thyroid hormone replacement therapy must have their hormone levels monitored to prevent hypothyroidism, which can cause cold intolerance and weight gain. For those treated with I-131, there is a low risk of temporary loss of or change in taste, as well as early- or late-onset effects such as dry mouth, dental caries, and damage to the salivary glands, which may also include difficulty swallowing. About 25% of medullary thyroid cancers are related to hereditary type 2 multiple endocrine neoplasia (MEN2) syndromes; these patients may be screened for other cancers and referred for genetic counseling and possible testing.<sup>108</sup>

## Urinary Bladder

It is estimated that there were 829,620 urinary bladder cancer survivors living in the US as of January 1, 2019, and an additional 80,470 cases will be diagnosed in 2019.

The majority of bladder cancer survivors are men, reflecting the fact that bladder cancer incidence is about 3 times higher in men than in women. The median age at diagnosis is 72.<sup>14</sup>

### Treatment and survival

Treatment of urinary bladder cancer varies by tumor stage and patient age. More than 70% of patients with bladder cancer are diagnosed with non-muscle-invasive disease (i.e., stages 0-I, including both in situ and invasive cancer that is present only in the very inner layers of bladder cells).<sup>64</sup> Stage 0 urinary bladder cancer is further divided into noninvasive papillary carcinoma, which can have a high or low risk of progression, and carcinoma in situ, which is generally high risk. Most non-muscle-invasive bladder cancer patients are diagnosed and treated with a minimally invasive procedure called transurethral resection of the bladder tumor (TURBT) (Figure 12). This endoscopic surgery may be followed by intravesical treatment (injected directly into the bladder) with either a chemotherapy drug or immunotherapy with bacillus Calmette-Guerin (BCG). Among patients with stage 0 disease, those with carcinoma in situ are substantially more likely to receive BCG immunotherapy than those with papillary carcinoma in situ (38% versus 13%, respectively).<sup>74</sup>

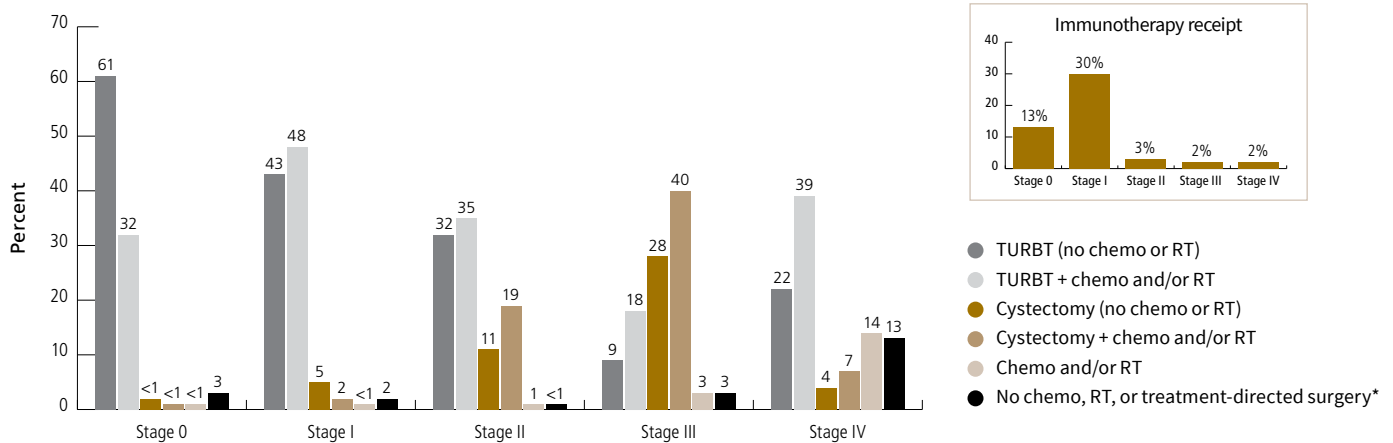
For muscle-invasive disease (stages II-IV), surgery may involve cystectomy, in which all or part of the bladder is removed, along with the surrounding fatty tissue and lymph nodes. Nearly one-third (30%) of stage II patients and about two-thirds (68%) of stage III patients receive cystectomy, with or without chemotherapy and/or radiation (Figure 12). In appropriately selected muscle-invasive cases, TURBT followed by combined chemotherapy and radiation is as effective as cystectomy at preventing recurrence.<sup>112-114</sup> Chemotherapy is usually the first treatment for cancers that have spread to other organs, but other treatments might be used as well. In recent years, immunotherapy with checkpoint inhibitors has become an important treatment option for advanced cancers, either following or in place of chemotherapy.

For all stages combined, the 5-year relative survival rate is 77%.<sup>14</sup> Stage 0 urinary bladder cancer is diagnosed in 47% of cases (Figure 4), for which 5-year survival is 95%.<sup>30</sup>

### Short- and long-term health effects

Posttreatment surveillance is crucial given the high rate of bladder cancer recurrence (ranging from 50%-90%).<sup>115, 116</sup> Surveillance can include cystoscopy (examination of the bladder with a small scope), urine cytology, and other urine tests for tumor markers. Patients with muscle-invasive

**Figure 12. Urinary Bladder Cancer Treatment Patterns (%), 2016**



RT = radiation therapy; Cystectomy = surgery that removes all or part of the bladder, as well as the surrounding fatty tissue and lymph nodes; TURBT = transurethral resection of the bladder tumor; Chemo = chemotherapy and includes targeted therapy but does not include immunotherapy, which is shown in the inset. \*These patients may have received a surgical diagnostic procedure to determine staging.

Source: National Cancer Data Base, 2016.

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disease may have additional tests, such as computed tomography scans of the chest, abdomen, and pelvis.

Partial cystectomy results in a smaller bladder, sometimes causing more frequent urination. Patients undergoing cystectomy in which the entire bladder is removed require urinary diversion with either a “new” bladder (known as a neobladder), created by connecting a small part of the intestine to the urethra, or a urostomy, which is a tube that empties into a bag worn outside of the abdomen or uses an internal valve (requiring self-catheterization). Those with a neobladder retain most of their urinary continence after appropriate rehabilitation.<sup>117</sup> However, creation of a neobladder remains much less common than a urostomy (9% versus 91%), largely due to the fact that the procedure is technically complex and often only offered at large hospitals with experienced surgeons.<sup>118</sup> Younger, healthier patients and those who are male are also more likely to undergo the procedure. Most patients with muscle-invasive disease treated with TURBT combined with chemotherapy and radiotherapy maintain full bladder function and good quality of life.<sup>119</sup> However, these patients require careful surveillance with regular cystoscopy and a complete cystectomy if the cancer recurs.

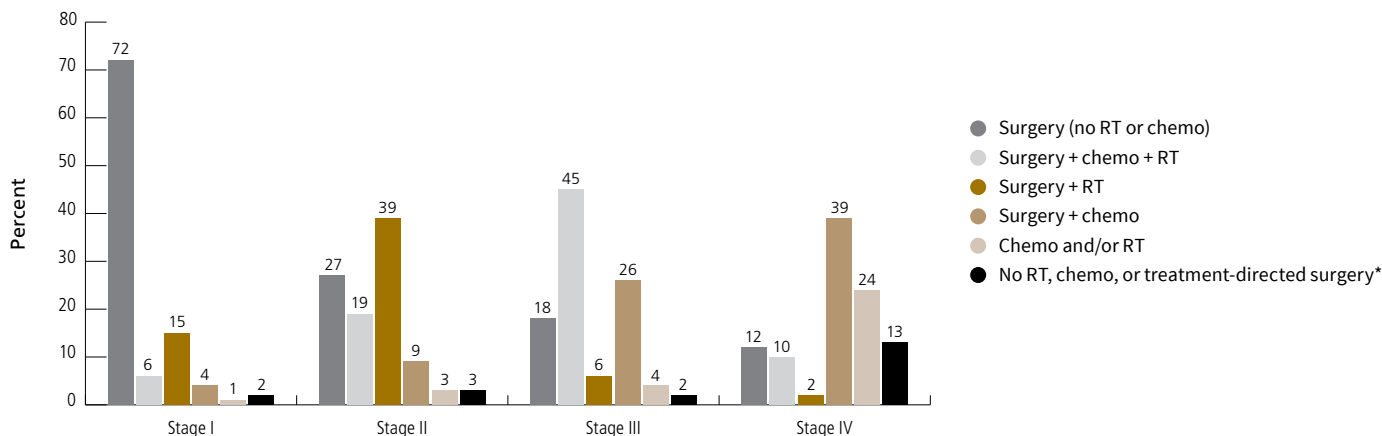
## Uterine Corpus

It is estimated that there were 807,860 uterine corpus cancer survivors living in the US as of January 1, 2019, and an additional 61,880 women will be diagnosed in 2019. Uterine cancer is the second most prevalent cancer among female cancer survivors, following breast cancer. More than 90% of cases occur in the endometrium (lining of the uterus); the majority of the remaining cases are uterine sarcomas.<sup>64</sup> The median age at diagnosis is 62.<sup>14</sup>

### Treatment and survival

Uterine cancers are usually treated with surgery, radiation, hormonal therapy, and/or chemotherapy, depending on stage and cancer type. Surgery consists of hysterectomy (removal of the uterus, including the cervix), often along with bilateral salpingo-oophorectomy (removal of both ovaries and fallopian tubes). Surgery without chemotherapy or radiation is used to treat most (72%) patients with stage I disease (Figure 13). About two-thirds (67%) of stage II patients and 77% of stage III patients receive surgery followed by radiation and/or chemotherapy (Figure 13). Clinical trials are currently assessing the most appropriate regimen of radiation, hormone therapy, and chemotherapy for women with metastatic or recurrent endometrial cancers.

Figure 13. Uterine Cancer Treatment Patterns (%), by Stage, 2016



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy. \*Some of these patients may have received hormonal therapy.  
**Source:** National Cancer Data Base, 2016.

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The 5-year relative survival for cancer of the uterine corpus is 81%.<sup>14</sup> About 6 in 10 cases are diagnosed at stage I (usually because of postmenopausal bleeding) (Figure 4), for which the 5-year survival is 96%.<sup>30</sup> The 5-year survival for white women (83%) is substantially higher than for black women (62%) for all stages combined, and is also higher for each stage.<sup>14</sup>

## Short- and long-term health effects

Any hysterectomy causes infertility, and bilateral salpingo-oophorectomy causes menopause in premenopausal women, which can result in symptoms such as hot flashes, night sweats, vaginal dryness, and osteoporosis. Sexual problems are commonly reported among uterine cancer survivors.<sup>39, 120</sup> Removing lymph nodes in the pelvis can lead to a buildup of fluid in the legs (lymphedema) that may worsen with radiation.<sup>121</sup>

# Navigating the Cancer Experience: Treatment and Supportive Care

Newly diagnosed cancer patients and their loved ones face numerous challenges and difficult decisions immediately after diagnosis. The following section provides information and resources for newly diagnosed patients, as well as information regarding supportive care and transitioning to long-term survivorship.

## Making Decisions about Cancer Care

### Choosing a Doctor and Treatment Facility

Typically, the doctor who diagnoses the cancer will recommend appropriate specialists, including specialized surgeons, medical oncologists, hematologists, and radiation oncologists. Some cancers, such as skin and prostate, may be treated by clinicians who specialize in specific body systems (i.e., dermatologists and urologists, respectively) rather than oncologists.

Help with choosing a doctor and treatment center, as well as information to prepare patients for meeting with their treatment team for the first time, is available from cancer.org. See Choosing Your Treatment Team for more information ([cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team.html](https://www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team.html)).

### Choosing among Recommended Treatments

Patients and family members may want to educate themselves about treatment options so they can be informed participants in treatment decisions. Helpful

information is available online at [prepareforyourcare.org](https://www.prepareforyourcare.org) to assist patients and families in communicating with each other and their care team. Visit [cancer.org/treatment](https://www.cancer.org/treatment) for a list of questions to ask when choosing among recommended treatment options, along with other information. For specific treatment information by cancer type, visit [cancer.org/cancer.html](https://www.cancer.org/cancer.html). It is important that treatment decisions take patients' preferences, needs, and desires into account, making discussion about these a fundamental part of the decision-making process.

## Cancer Rehabilitation

Cancer survivors' ability to function and quality of life may be significantly reduced because of preexisting medical conditions, the cancer itself, or side effects of cancer treatment. Examples of impairments include muscular weakness or paralysis, swallowing or speech problems, lymphedema (swelling caused by removal of or damage to lymph nodes), and physical disability as a result of major surgery. It is important to identify preexisting conditions as soon as possible after diagnosis and identify worsening or new issues all along the care continuum.<sup>3</sup> Cancer rehabilitation often involves an interdisciplinary approach and focuses on the diagnosis and treatment of specific cognitive and physical difficulties that are best addressed by qualified specialists such as physiatrists, who specialize in rehabilitation medicine, and physical, occupational, and speech therapists. For



some patients, providing “pre-rehabilitation,” or targeted interventions before treatment begins, may also be useful for improving physical and emotional recovery.<sup>122</sup> However, despite the high occurrence of cancer-related disability, rehabilitation is largely underutilized even for readily treatable impairments, with receipt among survivors ranging from 1%-2%.<sup>123</sup> As such, improving access to and use of rehabilitation among survivors has been identified as a priority for several organizations, including the American Cancer Society.

## Psychosocial Care

Cancer patients may have preexisting psychological or psychiatric conditions that impede their ability to cope with cancer, while other patients may develop psychological distress after diagnosis.<sup>124</sup> Up to one-half of cancer patients show a significant level of distress.<sup>125</sup> Early evaluation and screening for distress leads to early and timely management of symptoms, which in turn improves adherence to treatment, communication between patient and medical team, and fewer calls and visits to the oncologists' office. Evidence from randomized trials shows that psychological interventions in cancer patients with distress may lead to a survival advantage over those who do not receive psychosocial care.<sup>124</sup> However, less than half of distressed patients with cancer are identified and referred for psychosocial help. Barriers to distress management include under-recognition of psychological symptoms by both patients and provider teams, lack of knowledge regarding community resources, and perceived stigma associated with psychological distress. The National Comprehensive Cancer Network's Distress Management panel has proposed recommendations for recognizing and managing distress in cancer patients.<sup>124</sup>

## Palliative Care

The goal of palliative care is to alleviate symptoms associated with cancer and its treatment, such as pain, other physical symptoms, and emotional distress, with a specific focus on using family and patient communication to determine care goals.<sup>126</sup> Similar to cancer rehabilitation, palliative care improves quality of life for cancer patients

and their families and has also been shown to improve survival when combined with other treatments.<sup>127</sup> It is increasingly recommended alongside curative treatment for all newly diagnosed cancer patients, regardless of stage. Palliative care is provided in a variety of settings, including hospitals and community cancer centers, long-term care facilities, during hospice care, and even in the home. However, palliative care remains substantially underutilized in the United States; in one large study, only 10% of patients with solid tumors received palliative care.<sup>128</sup>

The American Cancer Society's nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network<sup>SM</sup>, is working to improve access to palliative care for all adults and children facing cancer and other serious illnesses. Visit [acscan.org/qualityoflife](https://acscan.org/qualityoflife) and [patientqualityoflife.org](https://patientqualityoflife.org) for more information. Visit the American Cancer Society website at [cancer.org/treatment/treatments-and-side-effects/palliative-care.html](https://cancer.org/treatment/treatments-and-side-effects/palliative-care.html) and [getpalliativecare.org](https://getpalliativecare.org) to learn more about palliative care or to find palliative care professionals.

## Transitioning to Long-term Survivorship

After primary treatment ends, most cancer patients transition to the recovery phase of survivorship. Challenges during this time may include the lingering effects of illness and treatment (e.g., fatigue, pain, bowel or bladder changes, sexual dysfunction); worry about recurrence; difficulty returning to former roles, such as that of parent or employee; anxiety about medical bills (see Financial Hardship among Cancer Survivors, [page 26](#)); and decisions about which provider to see for various health care needs. Regular medical care following primary cancer treatment is important because of the potential for lingering effects of treatment, as well as the risk of recurrence and additional cancer diagnoses. The American Cancer Society has begun to issue evidence- and consensus-based comprehensive survivorship care guidelines to aid primary care and other clinicians in addressing these and other concerns in adult survivorship care.<sup>35, 60, 129, 130</sup>

In 2006, the Institute of Medicine's Committee on Cancer Survivorship published a report highlighting the need for strategies to improve the coordination of ongoing care for survivors.<sup>131</sup> A follow-up report recommended that patients and their primary care providers be given a summary of their treatment and a comprehensive survivorship care plan developed by one or more

members of the oncology team.<sup>132, 133</sup> A recent meta-analysis reported that survivorship care plans did not improve quality of life outcomes, but could improve information received, care satisfaction, and receipt of recommended care; counseling to discuss the plan was important.<sup>134</sup> Research is ongoing to identify how to optimize the transition into long-term survivorship.

## Long-term Survivorship

The following section discusses common issues related to quality of life, risk of recurrence and subsequent cancers, and health behaviors of cancer survivors. Survivors are remarkably resilient, but some may have to make physical, emotional, social, and spiritual adjustments to their lifestyle – in other words, to find a “new normal.”

### Quality of Life

Quality of life is a broad multidimensional concept that considers a person's physical, emotional, social, and spiritual well-being. Approximately 1 in 4 cancer survivors report a decreased quality of life due to physical problems and 1 in 10 due to emotional problems.<sup>135</sup> Physical well-being is the degree to which symptoms and side effects, such as pain, fatigue, and poor sleep quality, affect the ability to perform normal daily activities. Emotional, or psychological, well-being refers to the the range of difficulty in coping with anxiety, depression, fear of cancer recurrence, and problems with memory and concentration. Social well-being refers to the health of relationships with family members and friends, including intimacy and sexuality. Employment and financial concerns also affect social well-being. Finally, spiritual well-being is derived from drawing meaning from the cancer experience, either in the context of religion or by maintaining hope and resilience in the face of uncertainty about one's future health.

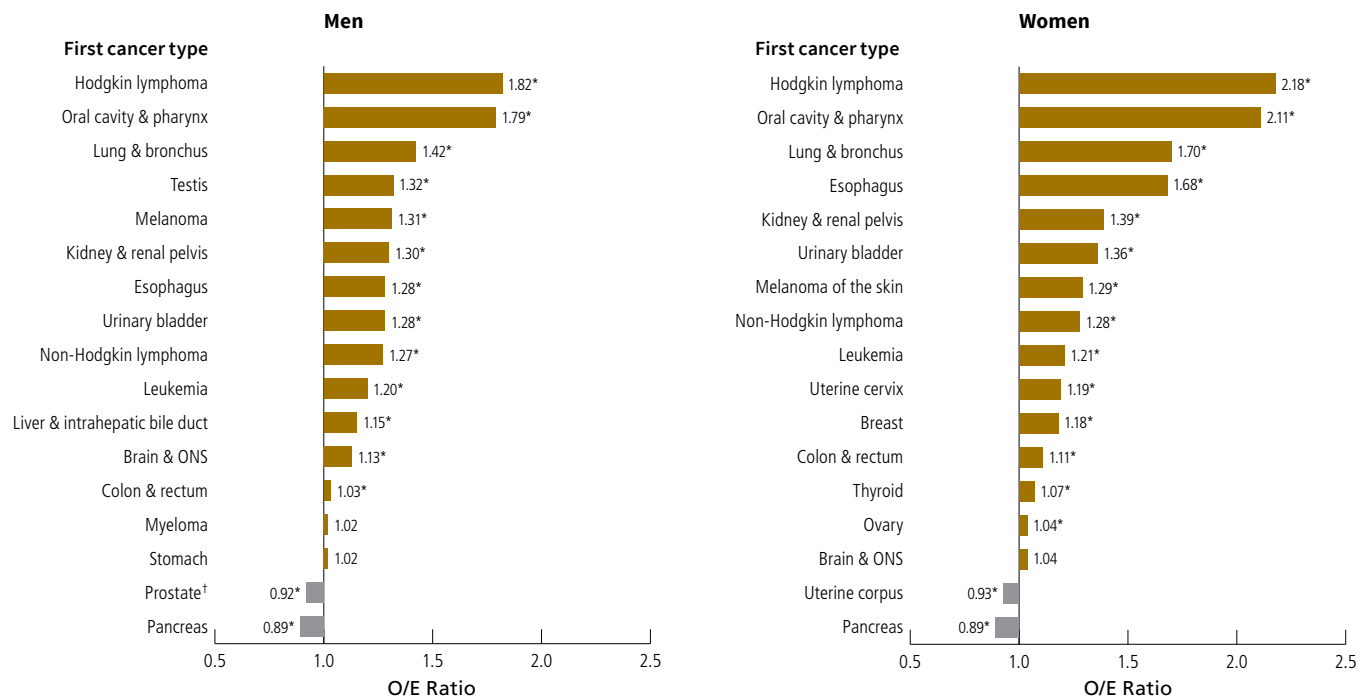
Emotional well-being among long-term cancer survivors (5 years or more) is comparable to that of those with no history of cancer, while overall physical well-being is lower.<sup>135, 136</sup> Not surprisingly, individuals who have a

history of more invasive and aggressive treatments tend to report poorer functioning and quality of life in the long term. Certain groups of survivors, such as racial/ethnic minorities and those of lower socioeconomic status, also report greater difficulty regaining quality of life.<sup>137, 138</sup> For example, one study of breast cancer survivors found that black women and women with lower socioeconomic status had poorer physical functioning than survivors of other races/ethnicities and with higher socioeconomic status.<sup>139</sup> In addition, survivors diagnosed at a younger age tend to have poorer emotional functioning, whereas older age at diagnosis is often associated with poorer physical functioning.<sup>135, 140, 141</sup> Many survivors of childhood cancer have cognitive or functional deficits that impact their ability to successfully complete their education and find employment, which in turn can impact psychological and financial well-being and lower quality of life.<sup>51, 142, 143</sup>

### Risk of Recurrence and Subsequent Cancers

Even after treatment appears to have been effective, cancer cells may persist and grow, which is referred to as recurrence. Recurrence can occur near the site of the original cancer (local recurrence), in lymph nodes near the original site (regional recurrence), or elsewhere in the body (distant recurrence or metastasis). Although national estimates of recurrence are not available because this information is not collected by cancer registries, studies show that recurrence rates vary depending on tumor characteristics, stage of disease, and treatment. For some types of cancer, such as prostate, there are formulas that can help estimate the risk of recurrence based on stage and other clinical information.<sup>144</sup>

**Figure 14. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Site and Sex, Ages 20 and Older, 1975-2015**



ONS = Other nervous system. \*The ratio of the number of subsequent cancers observed among cancer survivors to the number of cancers expected is statistically significant ( $p < 0.05$ ). †Prostate cancer excludes subsequent prostate cancers due to potential bias from coding rules.  
 NOTE: Observed-to-expected ratio is the number of cancers that were observed among cancer survivors in the SEER 9 areas, divided by the number of cancers expected in this population, calculated using the population-based age-specific incidence rates in the SEER 9 areas.  
 Source: Surveillance, Epidemiology, and End Results (SEER) Program, 9 SEER registries, National Cancer Institute.

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A subsequent (or multiple) primary cancer is a new cancer that is biologically distinct from the original cancer. Whether a cancer is a new primary or a recurrence is important because it determines prognosis and treatment. The risk of developing a subsequent primary cancer varies by the type of cancer first diagnosed (referred to as the first primary), treatment (e.g., radiation), age at diagnosis, and other factors. Ratios of the observed-to-expected number of cancer cases (O/E) among cancer survivors in population-based cancer registries are used to describe the risk for a subsequent cancer diagnosis, with the number expected based on cancer occurrence in the general population. As a whole, cancer survivors have a small increased risk of additional cancers. Risk is higher for those with a history of childhood cancer, as well as for adult survivors of Hodgkin lymphoma and tobacco-related cancers (oral cavity and pharynx, lung and bronchus, kidney and renal pelvis, esophagus, and urinary bladder)

(Figure 14). For example, female survivors of Hodgkin lymphoma treated with radiation to the chest during adolescence are at particularly increased risk of developing breast cancer. In addition to the carcinogenic effects of cancer treatment and shared risk factors, genetic susceptibility also influences risk.<sup>145</sup>

The American Cancer Society’s survivorship care guidelines include recommendations for clinicians regarding appropriate surveillance for recurrent and new primary cancers.<sup>35, 60, 128, 129</sup> Cancer survivors who have completed treatment should ask their provider about the appropriate timing and types of follow-up tests recommended to look for recurrent or new cancer. Health strategies to reduce the risk of recurrence and additional cancers, as well as improve survivor health and quality of life, are provided in *Regaining and Improving Health through Healthy Behaviors*, page 26.

## Financial Hardship among Cancer Survivors

Cancer survivors are vulnerable to financial hardship that may manifest as material (e.g., problems paying medical bills, medical debt, and bankruptcy), psychological (e.g., stress or worry about paying medical bills), or behavioral (e.g., delaying or forgoing necessary medical care because of cost) aspects. Survivors who are younger, underinsured or uninsured, and/or have lower income are more likely to experience financial hardship, as are long-term survivors of childhood cancer.<sup>142, 143, 146, 147</sup> For example, in one study, 35% of cancer survivors ages 18-49 years reported difficulty in paying medical bills compared to 25% in those without a history of cancer; this gap narrowed substantially in ages 50-64 years, 27% versus 23%, respectively.<sup>147</sup> Younger cancer survivors are also more likely to report multiple aspects of financial hardship and greater hardship intensity than older cancer survivors. Medical financial hardship is most prevalent among cancer survivors without health insurance.<sup>148</sup>

Even when survivors have private or government health insurance, out-of-pocket costs of cancer care often pose a significant financial burden for them and their families that continues long after initial treatment is completed.<sup>149</sup> The passage of the Affordable Care Act (ACA) in 2010 was intended to improve health insurance coverage options and population health. Provisions of the ACA include the introduction of the Health Insurance Marketplace, which allows individuals to enroll in private plans; dependent coverage expansion, which allows young adults to remain covered under a parents' private health insurance up until age 26 years; and expansion of Medicaid eligibility thresholds for low-income adults with and without children in some states. Between 2010 and 2014, the percentage of non-elderly cancer patients (<65 years of age) who were uninsured at diagnosis significantly decreased, especially among Medicaid expansion states.<sup>150</sup> Medicaid expansions were also associated with earlier stage disease among newly diagnosed cancer patients. Monitoring the effects of ACA provisions is ongoing, especially in relation to access to cancer treatment and survival.

## Regaining and Improving Health through Healthy Behaviors

Survivors who minimize their exposure to cancer risk factors can reduce the risk of recurrence, progression, and additional cancers. For example, lung cancer survivors who do not smoke cigarettes after treatment have a lower risk of recurrence compared to survivors who do smoke.<sup>151, 152</sup> In addition, healthy behaviors may improve survivor functioning and quality of life.<sup>153</sup> Exercise can improve heart and lung function and reduce cancer-related fatigue among survivors.<sup>154</sup> The growing evidence that healthy behaviors are beneficial to survivors led the American Cancer Society to develop a guideline for physical activity and nutrition for cancer survivors during and after treatment.<sup>155</sup> Since this guideline was originally released, a number of practical interventions for survivors addressing diet, weight, and physical activity have been developed and tested.<sup>156</sup>

**Smoking cessation.** Despite the fact that smoking interferes with some common cancer treatments and increases the risk for 12 different cancer types, heart disease, and many other chronic health conditions,<sup>157</sup> a significant number of cancer survivors, particularly those who are young, continue to smoke after their diagnosis. During 2008 to 2017, 31% of cancer survivors ages 18 to 44 years were current smokers compared to 19% of those in the general population.<sup>158</sup> Smoking cessation efforts are often most successful when they are initiated soon after diagnosis.<sup>159</sup> Follow-up support for survivors who quit, and for those who are not initially successful, is also needed because recent research found almost 10% of survivors were still smoking 9 years after diagnosis.<sup>160</sup> Increasing survivors' access to cessation aids, developing tailored interventions, and health systems' use of the 5 A's (Ask, Advise, Assess, Assist, Arrange) are likely to reduce smoking among cancer survivors. For more information on American Cancer Society resources for smoking cessation, see [page 31](#).

**Physical activity.** In patients who are physically able, physical activity can hasten recovery from the immediate side effects of treatment and prevent some long-term side effects, and may also reduce the risk of recurrence and

increase survival for some cancers.<sup>161</sup> In observational studies among breast cancer survivors, moderate physical activity has been associated with reduced risk of death from all causes (24%-67%) and breast cancer (50%-53%).<sup>162</sup> Similar benefits have been observed among colon cancer survivors.<sup>163</sup> Intervention studies have shown that exercise can improve fatigue, anxiety, depression, self-esteem, happiness, and quality of life in cancer survivors.<sup>161</sup>

Exercise recommendations should be tailored to the survivor's capabilities. Barriers to engaging in physical activity may be symptomatic (e.g., fatigue, pain, and nausea), physical (e.g., amputations, lymphedema, and neuropathy), psychosocial (e.g., feelings of fear, lack of motivation, or hopelessness), financial, or structural (e.g., unfavorable community environments). Physical impairments that would limit safe activity should be assessed by rehabilitation professionals before general exercise recommendations are made.<sup>3</sup>

**Nutrition, alcohol consumption, and maintaining a healthy body weight.** Weight management is an important issue for many survivors. Some patients are overweight or obese at the beginning of treatment and some may gain weight during treatment, while others may become underweight due to treatment-related side effects (e.g., nausea, vomiting, and difficulty swallowing).<sup>164</sup> Numerous studies have shown that obesity and weight gain in breast cancer survivors lead to a greater risk of recurrence and decreased survival; the evidence is less clear for colorectal and other cancers.<sup>165</sup> Obesity may also increase the risk of some treatment-related side effects, such as lymphedema and fatigue.<sup>166</sup>

A diet plentiful in fruit, vegetables, and whole grains with limited amounts of fat, red and processed meat, and simple sugars may reduce the risk of both developing subsequent cancers and the risk of chronic diseases.<sup>167</sup> Head and neck cancer survivors should be advised to limit alcohol consumption due to their risk of developing a subsequent cancer and other adverse alcohol-related effects.<sup>128</sup> Studies have also shown an increased risk of recurrence among breast cancer survivors who consume three to four alcoholic drinks per week.<sup>168</sup>

**Skin care behaviors.** Skin cancer survivors are particularly susceptible to developing subsequent skin cancers. In addition, survivors of other cancer types who have undergone radiation therapy are at an increased risk of skin cancer.<sup>169</sup> Behaviors that decrease the risk of skin cancer include wearing sunscreen and protective clothing and avoiding sunbathing and artificial tanning.

**Cancer screening.** In addition to any recommended surveillance for subsequent cancers or recurrence, it is important for cancer survivors to resume recommended screening for cancers for which they're at average risk of developing. Receiving recommended screening can detect cancer earlier, when treatment is often more likely to be successful, or, in the case of colorectal or cervical cancer, prevent cancer through the removal of precancerous lesions. In one meta-analysis, cancer survivors were about 20% more likely to report receiving screening for breast, cervical, and colorectal cancer compared with people without a history of cancer.<sup>170</sup> However, there is some evidence that overscreening among people with a history of cancer, particularly those with advanced disease, may lead to more harm than benefit.<sup>171</sup>

## Concerns of Caregivers and Families

As hospital space becomes more limited to acute care and cancer treatments are delivered more frequently in outpatient settings, the tremendous responsibility of picking up where the health team leaves off increasingly rests with survivors' loved ones. As such, effective integration of informal cancer caregivers into health care delivery teams is essential for optimizing outcomes for both survivors and their caregivers.<sup>172</sup>

Although increasing attention has been given to the need for greater surveillance of these caregivers and their needs, contemporary estimates of caregiver prevalence in the US continue to vary widely, ranging from 1.1 million to 6.1 million.<sup>173</sup> Most caregivers are the spouse (66%) or offspring (18%) of cancer patients, and caregivers are more likely to be women (65%) than men.<sup>174</sup> Caregiver responsibilities can include gathering information to advise treatment decisions, attending to treatment side effects, coordinating medical care, managing financial issues, and providing emotional support to the survivor. One study found that even more than a year after cancer diagnosis, caregivers were still spending an average of 8 hours per day providing some form of care, with the most associated with providing care for lung cancer patients.<sup>175</sup>

Caregivers report a variety of persistent unmet needs,<sup>176</sup> particularly among those who are providing end-of-life care.<sup>177,178</sup> In one study, about 40% of caregivers reported that they found caregiving emotionally difficult, and 12% reported experiencing depression.<sup>177</sup> Caregivers may feel unprepared and overwhelmed in their role, which can result in deterioration of their mental and physical health and a decline in quality of life, including an increased risk of developing chronic disease, depression, and anxiety.<sup>179</sup> Social support programs aimed at teaching effective coping skills can help buffer the negative consequences of caregiver stress.<sup>180-182</sup> Consultation with palliative care teams has also been shown to help ease family caregiver burdens. A systematic review suggested that caregivers benefit most from problem-solving and communication skills interventions.<sup>182</sup> Web-based interventions have also shown promising results in reducing caregiver burden and improving mood.<sup>181</sup> In addition, studies have shown that both survivors and their caregivers can benefit from the challenges associated with cancer, such as restoration of personal relationships, adoption of a more positive self-view, and becoming more empathetic.<sup>176,183</sup>

## The Future of Cancer Survivorship in the United States

As the population of cancer survivors in the US grows, it will become increasingly essential to optimize health care delivery and long-term outcomes among survivors and their caregivers. A recent report from the National Cancer Institute identified several persistent gaps in the funding of survivorship research for cancer types other than female breast, as well as for older survivors and racial/ethnic minorities.<sup>184</sup> Several organizations have also proposed recommendations for furthering progress in cancer survivorship in the US via innovative and standardized care delivery for survivors and caregivers.<sup>172,185</sup>

In particular, the American Cancer Society has set forth a “blueprint” to describe three priority areas for improving quality of life for long-term cancer survivors and their caregivers, including: 1) implementing routine needs assessment of survivors and caregivers; 2) facilitating personalized information and referrals from diagnosis onward for both survivors and caregivers; and 3) disseminating and supporting the implementation of new care methods and interventions.<sup>172</sup>

## Tools for Cancer Survivors and Caregivers

A number of tools to help survivors and caregivers have been developed through collaborations between the American Cancer Society and other institutions, including the George Washington University Cancer Institute, the Centers for Disease Control and Prevention, and the National Cancer Institute. These include:

**Life After Treatment Guide** – a quick, easy-to-read information guide to help cancer survivors and their caregivers understand the various aspects of the survivorship journey. The guide includes trusted resources for survivorship information and tips on how to communicate with health care providers. Visit [cancer.org/survivorshipguide](https://cancer.org/survivorshipguide) for a copy of the guide.

**Springboard Beyond Cancer** – Recognizing the lack of a free, comprehensive, online self-management tool specifically built for cancer survivors and caregivers, the American Cancer Society and the National Cancer Institute (NCI) began a joint venture and launched such a tool in October 2016. The eHealth tool includes interactive tools to help survivors implement self-management strategies, including, but not limited to, symptoms (e.g., fatigue, pain, sexual problems, weight gain), stress and mood (e.g., anxiety, depression, distress, fear of recurrence, mindfulness), wellness (getting active, healthy eating, quitting smoking), and getting support (from your health care team, family/friends/caregivers, at work, and peer-to-peer support).

**Caregiver Resource Guide** – The American Cancer Society is committed to providing much-needed support to the family members and friends who provide care to their loved one with cancer. As part of this commitment, targeted information, education, and support has been developed to meet their needs. Our *Caregiver Resource Guide* is designed to improve their: a) confidence in their role as a caregiver; b) caregiving skills in key areas; c) ability to manage their own health and wellness (psychosocial and physical); and d) access to services through multiple modalities and channels. Visit [cancer.org/caregiverguide](https://cancer.org/caregiverguide) to download.

**Caregiver Support Video Series** – Caregivers often feel unprepared to care for their loved one. Our *Caregiver Support Video Series* was developed to provide educational support to caregivers as they assist with the everyday needs of cancer patients and provide self-care techniques to improve their quality of life. Topics include: a) caregiver self-care (nutrition, physical activity, stress management and coping, dealing with fear of recurrence, and deep breathing/meditation); b) advocacy, or how to effectively communicate the patient's needs; and c) physical care training (drain care, lifting, pain management, medication management, symptom/side effect management, and identifying signs of infection). Visit [cancer.org/caregivervideos](https://cancer.org/caregivervideos) to watch the series.

## Tools for Health Care Professionals

Tools to help health care professionals deliver better survivorship care include:

**Adult Posttreatment Cancer Survivorship Care Guidelines** – a series of guidelines developed to assist primary care providers and other clinicians as they provide long-term, clinical follow-up care for cancer survivors, including surveillance for recurrence, screening for new cancers, management of chronic and late effects, support for health behavior changes, and referrals for rehabilitation, psychosocial, and palliative care needs or other specialty care. Guidelines for survivors of prostate, female breast, colorectal, and head and neck cancers have been released. (Visit [cancer.org/professionals](https://cancer.org/professionals) for copies of the guidelines.) An overview of this ongoing work, available at [bit.ly/SurvivorshipCenter](https://bit.ly/SurvivorshipCenter), was previously published. To facilitate delivery of this care, a toolkit was developed that includes resources to help clinicians implement these guidelines, along with information about provider training opportunities and patient materials. (Visit [bit.ly/NCSRCToolkit](https://bit.ly/NCSRCToolkit) for copies of the toolkit.)

**A Cancer Survivor's Prescription for Finding Information** – a tool to help health care professionals talk to survivors about resources available in their office or clinic, in the community, online, and over the phone. Visit [cancer.org/survivorshipprescription](https://cancer.org/survivorshipprescription) for a copy of the tool.

**Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide** – a brief guide that details indicators and outcome measures that can be used to monitor the success of survivorship programs. Visit [cancer.org/survivorshipprogramevaluation](https://cancer.org/survivorshipprogramevaluation) for a copy.

**Guide for Delivering Survivorship Care** – a guide that provides health care professionals with the knowledge, tools, and resources to deliver high-quality cancer survivorship care to cancer survivors. Visit [smhs.gwu.edu/gwci/survivorship/ncsrc/guidequalitycare](https://smhs.gwu.edu/gwci/survivorship/ncsrc/guidequalitycare) for a copy.

**Cancer Survivorship E-Learning Series for Primary Care Providers** – a free online continuing education program designed to educate primary care providers on the care needs of cancer survivors, and on the cancer survivorship care guidelines to help them provide clinical follow-up care for cancer survivors. Visit [cancersurvivorshipcentereducation.org](https://cancersurvivorshipcentereducation.org) to access the series online.

**Smartphone App for Clinicians** – a free mobile app is available to house content from the breast, colorectal, head and neck, and prostate cancer survivorship care guidelines. The app makes this content available for clinicians as a tool for use in the clinical encounter.

## Tools for cancer advocates and policy makers

**Cancer Survivorship: A Policy Landscape Analysis** – a white paper designed to educate policy makers on survivorship issues and describe the priority areas for improving cancer survivorship care. Visit [cancer.org/survivorshippolicypapers](https://cancer.org/survivorshippolicypapers) for a copy of the paper.

# The American Cancer Society

## How the American Cancer Society Saves Lives

With a dedicated team of volunteers and staff, the American Cancer Society is leading the fight for a world without cancer.

### Prevention and Early Detection

Smoking still causes about 30% of all cancer deaths in the US, including more than 80% of lung cancer deaths. The American Cancer Society continues our long history of work to reduce tobacco use through research (see [page 34](#)), education, and advocacy (see [page 34](#)). Our Center for Tobacco Control is working toward the adoption and implementation of smoke- and tobacco-free policies in all workplaces, public places, and other important venues such as multiunit residential settings. In addition, we're taking an increasingly proactive role in addressing the changing landscape related to rapidly emerging tobacco-related markets, including for electronic smoking products such as e-cigarettes.

For Americans who do not smoke, the most important way to reduce cancer risk is to maintain a healthy, active lifestyle. The American Cancer Society regularly performs a formal review of the current scientific evidence on diet and cancer and synthesizes it into clear, informative recommendations for the general public to promote healthy individual behaviors and environments that support healthy eating and physical activity to reduce cancer risk. These nutrition and physical activity guidelines form the foundation for our communication, worksite, school, and community strategies designed to encourage and support people in making healthy lifestyle behavior choices.

Finding cancer at its earliest, most treatable stage gives patients the greatest chance of survival. Moreover, screening tests for cervical and colorectal cancer can detect precancers, allowing for cancer prevention. To help the public and health care providers make informed decisions about cancer screening, the American Cancer

Society publishes early-detection guidelines based on the most current scientific evidence for cancers of the breast, cervix, colorectum, endometrium, lung, and prostate. In addition, the American Cancer Society has a history of implementing aggressive campaigns to increase awareness among the public and health care professionals of the value of cancer screening. Campaigns to increase use of Pap testing and mammography have helped contribute to a 71% decrease in cervical cancer mortality since 1969 and a 40% decline in breast cancer mortality since 1989, respectively. Building on these successes, the American Cancer Society and the National Colorectal Cancer Roundtable (NCCRT) launched an initiative in 2014 to increase colorectal cancer screening rates to 80% nationwide in adults 50 and older by 2018. More than 1,700 organizations have committed to this shared goal, and this dedication to collective action is working. Colorectal cancer screening rates have improved in most states, and an additional 3.3 million people were screened between 2014 and 2016. However, there are still too many communities with lower screening rates. In response, the American Cancer Society, the CDC, and the NCCRT introduced the 80% in Every Community campaign in 2019. The new campaign continues the momentum in bringing down barriers to screening, and its mission will not be achieved until every community benefits from screening rates of 80% and higher.

Similarly, seeing the need to reduce the incidence of and mortality from human papillomavirus (HPV)-associated cancers, we provide guidelines for HPV vaccination and established the National HPV Vaccination Roundtable, which is working with health care professionals nationwide to increase HPV vaccination rates in adolescents. With a variety of programs such as the NCCRT, the National HPV Vaccination Roundtable, and the Community Health Advocates implementing Nationwide Grants for Empowerment and Equity (CHANGE) program, we work with community health partners and corporations across the nation to increase access to preventive care and improve health equity. Together in 2018, we contributed to nearly 91,700 low- or



no-cost screening exams in underserved communities. By helping local facilities provide cancer education and screening for more underserved patients, we are helping to reduce death rates from breast, cervical, and colorectal cancers.

Through our Vaccinate Adolescent Programs, Cancer Control staff have implemented structured HPV vaccination interventions and Maintenance of Certification intervention projects in 91 federally qualified health care centers. Our staff have trained over 10,000 providers on HPV vaccination as cancer prevention. Clinics have seen an average HPV series initiation rate increase of 16% over the course of our year-long intervention projects.

More than 5 million new cases of skin cancer will be diagnosed in the US in 2019. That's why the American Cancer Society and other members of the National Council on Skin Cancer Prevention have designated the Friday before Memorial Day as Don't Fry Day. We promote skin cancer prevention and awareness educational messages in support of Don't Fry Day and year-round.

The American Cancer Society also works with companies across the US to help their employees learn more about taking action to help reduce their cancer risk. We work alongside employers to strengthen a culture of health and provide employee-focused resources and information.

Some products we offer include:

**The Quit For Life® Program:** This is the nation's leading tobacco cessation program, offered by 25 states and territories, including Guam and Washington, DC, and more than 700 employers and health plans throughout the US. Operated and managed by Optum, the program is built on the organizations' more than 35 years of combined experience in tobacco cessation. It employs an evidence-based combination of physical, psychological, and behavioral strategies to enable participants to overcome their addiction to tobacco. A critical mix of medication support, phone-based cognitive behavioral coaching, text messaging, web-based learning, and support tools produces a higher-than-average quit rate.

**The Freshstart® program:** This group-based tobacco cessation program is designed to help employees plan a successful quit attempt by providing essential information, skills for coping with cravings, and social support. The program is delivered through hospital systems, employers, military bases, universities/colleges, community health organizations, and other systems.

**The 80% Pledge for Colorectal Cancer – Employers guide:** This detailed guide includes steps to follow to increase colorectal cancer screening in the workplace, including making the commitment; working with health plans and wellness staff to ensure coverage is understood, promoted, and designed effectively; capturing data to show progress; and sharing effective strategies with the public.

**The Content Subscription Service:** This electronic toolkit subscription is offered by the American Cancer Society to employers who support the health and wellness needs of employees with information about cancer prevention and early detection.

**The *Healthy Living* newsletter:** Produced by the American Cancer Society, this monthly electronic newsletter teaches the importance of making healthy lifestyle choices. The e-newsletter focuses on exercising, eating better, and maintaining a healthy weight. *Healthy Living* is available in both English and Spanish, and the content has been edited by our scientific staff to ensure that the most up-to-date and accurate information is being provided.

## Cancer Information

Caring, trained American Cancer Society staff connect people to answers about a cancer diagnosis, health insurance assistance, American Cancer Society programs and services, and referrals to other services at our 24/7 helpline at 1-800-227-2345. Our website, [cancer.org](https://www.cancer.org), offers reliable and accurate cancer information and news, including current information on treatments and side effects for every major cancer type, and programs and services nearby. We also help people who speak languages other than English or Spanish find the assistance they need at [cancer.org/easyreading](https://www.cancer.org/easyreading) or [cancer.org/cancer-information-in-other-languages](https://www.cancer.org/cancer-information-in-other-languages).

The American Cancer Society also publishes brochures and books that cover a multitude of topics, from patient education, quality of life, and caregiving issues to healthy living. Visit [cancer.org/bookstore](https://cancer.org/bookstore) for a list of books that are available to order. All of our books are also available from all major book retailers such as Amazon and Barnes & Noble. Call 1-800-227-2345 or visit [cancer.org](https://cancer.org) for brochures. We also publish three peer-reviewed scientific journals for health care providers and researchers: *Cancer*, *Cancer Cytopathology*, and *CA: A Cancer Journal for Clinicians*. Visit [cancer.org/health-care-professionals/resources-for-professionals.html](https://cancer.org/health-care-professionals/resources-for-professionals.html) to learn about the journals and their content.

## Programs and Services

**Survivorship.** American Cancer Society survivorship work aims to help people living with and beyond cancer from diagnosis through long-term survivorship to the end of life. Efforts focus on helping survivors understand and access treatment; manage their ongoing physical, psychosocial, and functional problems; and engage in healthy behaviors to optimize their wellness. Our posttreatment survivorship care guidelines are designed to promote survivor healthiness and quality of life by facilitating the delivery of high-quality, comprehensive, coordinated clinical follow-up care. Our survivorship research efforts focus on understanding the impact of cancer on multiple facets of survivors' lives and on developing and testing interventions to help survivors actively engage in their health care and improve their health and well-being through and beyond treatment. Through the National Cancer Survivorship Resource Center, a collaboration between the American Cancer Society and the George Washington University Cancer funded by the Centers for Disease Control and Prevention, we created the Cancer Survivorship E-Learning Series for Primary Care Providers. The free e-learning program is designed to teach clinicians how to care for survivors of adult-onset cancers.

**Support for caregivers.** Contemporary estimates of caregiver prevalence range between 1.1 million and 6.1 million individuals, and we are committed to meeting their information, education, and support needs. We support the notion that cancer is not isolated only to

the individual diagnosed but also impacts an entire family unit and network of close friends. One of the informational tools we offer caregivers is our *Caregiver Resource Guide*, which can help them: learn to care for themselves as a caregiver, better understand what their loved one is going through, develop skills for coping and caring, and take steps to help protect their own health and well-being.

**Help navigating the health care system.** Learning how to navigate the cancer journey and the health care system can be overwhelming for anyone, but it is particularly difficult for those who are medically underserved, those who experience language or health literacy barriers, and those with limited resources. The American Cancer Society Patient Navigator Program reaches those most in need. It has specially trained patient navigators across the country who can help: find transportation to treatment and other cancer-related appointments; assist with medical financial issues, including insurance navigation; identify community resources; and provide information on a patient's cancer diagnosis and treatment process. In 2018, more than 34,000 people relied on the program to help them through their diagnosis and treatment.

**Transportation to treatment.** One of the biggest roadblocks to treatment can be the lack of transportation. That's why the American Cancer Society started the Road To Recovery® program. It's at the very heart of our work of removing barriers to quality health care by providing patients transportation to treatment through volunteer drivers, partners, or community organizations. In 2018, we provided more than 480,000 rides to more than 28,000 cancer patients. Other transportation programs are also available in certain areas.

**Lodging during treatment.** The American Cancer Society Hope Lodge® program provides a free home away from home for cancer patients and their caregivers. More than just a roof over their heads, it's a nurturing community that helps patients access the care they need. In 2018, more than 30 Hope Lodge locations provided nearly 477,000 nights of free lodging to more than 27,000 patients and caregivers – saving them an estimated \$49 million in hotel expenses. Through our Hotel Partners

Program, we also partner with local hotels to provide free or discounted lodging for patients who are not able to make frequent trips for treatment appointments.

**Breast cancer support.** Through the American Cancer Society Reach To Recovery® program, breast cancer patients are connected with trained volunteers who have had similar diagnoses and treatment plans to provide peer-to-peer support on everything from practical and emotional issues to helping them cope with their disease, treatment, and long-term survivorship issues. In 2018, the program provided more than 5,400 visits.

**Hair-loss and mastectomy products.** The American Cancer Society “*tlc*” Tender Loving Care® publication offers affordable hair loss and mastectomy products for women coping with cancer, as well as advice on how to use them. Products include wigs, hairpieces, hats, turbans, breast forms, and mastectomy bras, camisoles, and swimwear. The “*tlc*”™ products and catalogs are available online at [tlcdirect.org](http://tlcdirect.org) or by calling 1-800-850-9445.

**Finding hope and inspiration.** The American Cancer Society Cancer Survivors Network® provides a safe online connection where cancer patients can find others with similar experiences and interests. At [csn.cancer.org](http://csn.cancer.org), members can join chat rooms and build their own support network from among the members. Other online resources, including MyLifeLine and Springboard Beyond Cancer, provide additional support for patients, survivors, and caregivers and allow them to better communicate to receive the help they need during and after cancer.

## Other Sources of Survivor Information and Support

### *CancerCare*

1-800-813-HOPE or 1-800-813-4673

[cancercares.org](http://cancercares.org)

*CancerCare* provides professionally facilitated support services for anyone affected by cancer, including a toll-free counseling line, various support groups (online, telephone, or face-to-face), and Connect Education Workshops.

### Cancer Support Community

1-888-793-9355

[cancersupportcommunity.org](http://cancersupportcommunity.org)

Through a nonprofit network of cancer support worldwide, Cancer Support Community (CSC) offers free support services through professionally led community-based centers, hospitals, community oncology practices, and online communities. The CSC is focused on providing essential, but often overlooked, services, including support groups, counseling, education, and healthy lifestyle programs. In collaboration with the LIVESTRONG Foundation, the CSC developed the Cancer Transitions program for posttreatment cancer survivors, which covers the benefits of exercise, nutrition, relaxation, emotional support, and medical management.

### LIVESTRONG Foundation

1-855-220-7777

[livestrong.org](http://livestrong.org)

The LIVESTRONG Foundation fights to improve the lives of people affected by cancer. Created in 1997, the foundation provides free services and resources that help improve patient and survivor outcomes and address the practical, emotional, employment and financial challenges that come with cancer. LIVESTRONG has also partnered with the YMCA to provide a 12-week program promoting physical activity after a cancer diagnosis ([livestrong.org/what-we-do/program/livestrong-at-the-ymca](http://livestrong.org/what-we-do/program/livestrong-at-the-ymca)).

### National Coalition for Cancer Survivorship

1-877-NCCS-YES or 1-877-622-7937

[canceradvocacy.org](http://canceradvocacy.org)

The National Coalition for Cancer Survivorship offers free publications and resources that empower people to become strong advocates for their own care or the care of others. The coalition’s flagship program is the award-winning Cancer Survival Toolbox, a self-learning audio series developed by leading cancer organizations to help people develop crucial skills to understand and meet the challenges of their illness.

## National Alliance for Caregiving (NAC)

1-301-718-8444

[caregiving.org](http://caregiving.org)

The NAC is a nonprofit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

## Patient Advocate Foundation

1-800-532-5274

[patientadvocate.org](http://patientadvocate.org)

The Patient Advocate Foundation (PAF) is a national nonprofit organization that seeks to safeguard patients through effective mediation, assuring access to care, maintenance of employment, and preservation of financial stability. The PAF serves as an active liaison between patients and their insurer, employer, and/or creditors to resolve insurance, job retention, and/or debt crisis matters relative to their diagnosis through professional case managers, doctors, and health care attorneys.

## Research

Research is at the heart of the American Cancer Society's mission. For more than 70 years, we have invested in innovative research, all to find the causes, preventions, and better treatments for cancer, as well as ways to help people thrive during and after treatment. The top-tier facilities and programs we fund study everything from nutrition to genetics to environmental and even behavioral factors to find answers that lead to understanding, resulting in more effective treatments.

As of February 19, 2019, the American Cancer Society is funding more than \$67 million in cancer treatment research and approximately \$91 million in cancer control, survivorship, and outcomes research. We have awarded 82 grants in symptom management and palliative care focused on patient, survivor, and quality of life research. Of those, 11 grants were funded through a partnership with the National Palliative Care Research Center over the past 10 years, with three new grantees added in 2019.

Specific examples of ongoing and recent intramural and extramural research include:

- Testing whether an eight-week mobile app-based mindfulness program is accepted and useful for patients receiving chemotherapy and their caregivers
- Developing and providing a training on fear of cancer recurrence among cancer survivors to multidisciplinary primary care providers
- Examining a dyadic yoga program in couples coping with lung cancer
- Testing an intervention involving systematic light exposure to treat cancer-related fatigue in prostate cancer patients receiving radiation therapy
- Exploring the burden of treatment experienced by cancer patients with comorbid conditions
- Testing a self-management intervention combining personalized education and exercise advice to help control joint pain in older breast cancer survivors after beginning hormonal therapy
- Exploring the use of patient-reported outcome measures in cancer care (e.g., distress screening) at Commission on Cancer-accredited cancer centers
- Examining interactions between cancer patients and their caregivers to identify strategies that can enhance survivor-caregiver relationships and quality of life, particularly among medically underserved survivors
- Developing and testing an eHealth tool to help cancer survivors and caregivers self-manage their most pressing cancer-related issues

## Advocacy

Saving lives from cancer is as much a matter of public policy as scientific discovery. Lawmakers at the local, state, and federal level play a critical role in enacting policies that help save lives – from quality, affordable health care for all Americans; increasing funding for cancer research and programs; and improving quality of life for patients and their families, to helping communities prevent cancer and promote good health.

The American Cancer Society Cancer Action Network (ACS CAN), the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN empowers advocates across the country to make their voices heard and influence evidence-based public policy change as well as legislative and regulatory solutions that will reduce the cancer burden.

Created in 2001, ACS CAN is the force behind a powerful grassroots movement uniting and empowering cancer patients, survivors, caregivers, and their families to save lives from cancer. As the nation's leading voice advocating for public policies that help to defeat cancer, ACS CAN works to encourage elected officials and candidates to make cancer a top national priority. In recent years, ACS CAN has successfully worked to pass and implement laws at the federal, state, and local levels that: assure cancer patients and survivors have access to adequate and affordable health insurance coverage; increase funding for groundbreaking cancer research; improve access to prevention and early detection measures, treatment, and follow-up care; and improve quality of life for cancer patients and survivors.

ACS CAN's advocacy priorities on behalf of cancer patients and their families are outlined in the following sections.

### Access to Care

ACS CAN continues to advocate to protect key patient protections enacted as part of the Patient Protection and Affordable Care Act (ACA), including eliminating insurance coverage exclusions, preventing preexisting condition exclusions, eliminating annual and lifetime benefit caps, maintaining essential health benefit coverage requirements, and removing copays for key cancer prevention and early-detection services like mammography and colonoscopy. The organization is actively working with states to expand eligibility for Medicaid programs, allowing millions of low-income individuals and families to gain access to comprehensive and affordable health care coverage. Additionally, ACS CAN urges policy makers to advance and support policies

that protect and improve low-income Americans' access to health care to improve health outcomes and reduce the burden of cancer.

ACS CAN is also advocating for other important patient protections, including:

- The prohibition of short-term limited-duration plans, association health plans, and other plans that do not cover comprehensive benefits or protect patients against high needs and costs
- Market stabilization measures, including state individual mandates for insurance coverage
- Full federal funding for community health centers, which provide community-oriented primary care in underserved areas
- Access to preventive services without cost sharing

### Research Funding and Drug Development

ACS CAN is a leader in the effort to ensure full funding for the nation's public cancer research institutions, including the National Institutes of Health and its National Cancer Institute. Each year, nearly \$5 billion in grant funding for cancer research is distributed to investigators working in cancer centers, universities, and labs in every state of the country. Federal budget pressures threaten this funding every year, and ACS CAN views this driver of the research pipeline to be of prime importance in the search for cures, and fights not only to protect this funding, but also to expand it.

In addition to advocating for cancer research funding, ACS CAN works to increase cancer patient access to innovative therapies by improving clinical trial enrollment. Clinical trials are the key step in advancing potential new cancer treatments from the research setting to the cancer care clinic, and patient participation in trials is crucial to their success. Around 20 percent of cancer clinical trials fail due to insufficient patient enrollment. To improve enrollment, ACS CAN, in collaboration with other cancer stakeholders, identified and is working on a set of consensus recommendations to improve clinical trial enrollment.

## Prevention and Early Detection

ACS CAN is supporting policies that focus on the prevention and early detection of cancer by ensuring access to evidence-based prevention and early detection services, reducing tobacco use and exposure to secondhand smoke, promoting healthy eating and active living, reducing exposure to UV radiation emitted by indoor tanning devices, and increasing uptake of the HPV vaccination to help prevent cancer.

## Quality of Life

ACS CAN supports balanced pain policies at the federal and state levels that ensure continued patient and survivor access to pain treatments. The organization also supports the enactment of the Palliative Care and Hospice Education and Training Act to assure that cancer patients have full access to palliative care services, along with curative treatment, from the point of diagnosis through treatment and survivorship or end of life as

needed. The legislation provides for increased training and professional development in palliative care, a nationwide public and provider education campaign to disseminate information about the benefits of palliative care, and additional research on pain and symptom management with the intent of improving patient care.

Central to ACS CAN's success is the sophisticated and effective volunteer structure. Across the country, volunteers in every congressional district work closely with ACS CAN to organize and execute advocacy campaigns. Together, these committed volunteers recruit and support other volunteers dedicated to the most critical components of successful advocacy campaigns. They include grassroots mobilization, media outreach, fundraising, and integrating advocacy into the American Cancer Society Relay For Life®, Making Strides Against Breast Cancer®, Colleges Against Cancer® and Coaches vs. Cancer® signature programs and events.

# Sources of Statistics

**Prevalence.** Cancer prevalence was projected using the Prevalence, Incidence Approach Model, a method that calculates prevalence from cancer incidence, cancer survival, and all-cause mortality.<sup>186</sup> Incidence and survival were modeled by cancer type, sex, and age group using malignant cancer cases diagnosed during 1975-2015 from the nine oldest registries in the Surveillance, Epidemiology, and End Results (SEER) program (2017 data submission). Incident cases included the first diagnosed cancer for a specific cancer type from 1975 to 2015. Mortality data for 1975 to 2015 were obtained from the National Center for Health Statistics. Population estimates and projections through 2030 were obtained from the US Bureau of Census. Projected US incidence and mortality for 2016 to 2030 were calculated by applying 5-year average rates (2011-2015) to the respective US population projections by age, sex, race, and year. Survival, incidence, and all causes of mortality were assumed to be constant from 2016 through 2030. For more information on this method, please see publications by Mariotto et al.<sup>187</sup>

**New cancer cases.** The number of new cancer cases in the US in 2019 was published previously.<sup>188</sup> The estimates were calculated using a spatiotemporal model based on incidence data from 49 states and the District of Columbia for 2001 to 2015 that met the North American Association of Central Cancer Registries' high-quality data standard for incidence. This method considers geographic variations in sociodemographic and lifestyle factors, medical settings, and cancer screening behaviors as predictors of incidence, and also accounts for expected delays in case reporting.

**Survival.** This report presents relative survival rates to describe cancer survival for selected cancers. Relative survival adjusts for normal life expectancy (and events such as death from heart disease, accidents, and diseases of old age) by comparing survival among cancer patients to that of people not diagnosed with cancer who are of the same age, race, and sex. Five-year survival statistics for all stages combined presented in this publication were originally published in the National Cancer

Institute's *Cancer Statistics Review 1975-2015*.<sup>14</sup> Current survival estimates are based on cases diagnosed during 2008 to 2014 and followed through 2015 from the 18 SEER registries.<sup>30</sup> However, when describing changes in 5-year relative survival over time, survival rates were based on cases from the 9 SEER registries.<sup>66</sup> These survival statistics are generated using the National Cancer Institute's SEER\*Stat software version 8.3.5.<sup>189</sup>

**National Cancer Data Base.** The National Cancer Data Base (NCDB) is a hospital-based cancer registry jointly sponsored by the American Cancer Society and the American College of Surgeons, and includes more than 70% of all malignant cancers in the United States from more than 1,500 facilities accredited by the American College of Surgeons' Commission on Cancer (CoC). The NCDB contains standardized data regarding patient demographics, cancer type, and staging, as well as first course of treatment. The NCDB also collects detailed treatment information on radiation and systemic therapies, which is limited or unavailable in population-based registry data. Visit the SEER-Rx website, [seer.cancer.gov/tools/seerrx](http://seer.cancer.gov/tools/seerrx), for further information regarding the classification of anti-cancer drugs into the categories of chemotherapy, immunotherapy, hormonal therapy, and targeted therapy.

Although the NCDB is a useful tool in describing cancer treatment at a national level, it may not be fully representative of all cancer patients treated in the United States. Data are only collected for patients diagnosed or treated at CoC-accredited facilities, which are more likely to be located in urban areas and tend to be larger centers compared to non-CoC-accredited facilities. Additionally, cancers that are commonly treated and diagnosed in non-hospital settings (e.g., melanoma, prostate cancer, and nonmuscle invasive bladder cancer) are less likely to be captured by the NCDB because it is a hospital-based registry. Visit [facs.org/cancer/ncdb](http://facs.org/cancer/ncdb) for more information about the NCDB.

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